The factors that determine successful follow up of children diagnosed with incurable blindness using Health Information collected during their visits to The Red Cross Children's Hospital.

By

NOLUTHANDO MJWANA

(MJWNOL001)

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN

In partial fulfilment of the requirements for the degree

Master of Public Health (MPH) - Community Eye Health

Faculty of Health Sciences

12 February 2024

SUPERVISOR : DR. DEON MINNIES

CO-SUPERVISORS : DR ABRAM OPARE

: DR NICOLA FREEMAN

School of Public Health and Family Medicine

DECLARATION

I, Noluthando Mjwana, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: ….. Signed by candidate

Date: ……12 February 2024…….

Plagiarism Declaration

"This thesis/dissertation has been submitted to the Turnitin module (or equivalent similarity and originality checking software) and I confirm that my supervisor has seen my report and any concerns revealed by such have been resolved with my supervisor."

Name: Noluthando Mjwana

Student number: MJWNOL001

Signature: Signed by candidate

Date:
12/02/24

Outline

The factors that determine successful follow up of children diagnosed with incurable blindness using Health Information collected during their visits to The Red Cross Children's Hospital.

Part A research protocol

Part B literature review of articles on childhood blindness

Part C The main article of the research study; the methodology, results, discussion and conclusion of the findings.

LIST OF ABBREVIATIONS

ASfTB	Athlone School for The Blind
CBR	Childhood Blindness Registry
KI	Key Informant
KIM	Key Informant Method
LMIC	lower- and middle-income countries
RXH	Red Cross War Memorial Children's Hospital
RAAB	Rapid Assessment of Avoidable Blindness
WHO	World Health Organisation

TABLE OF CONTENTS

THE FACTORS THAT DETERMINE SUCCESSFUL FOLLOW UP OF CHILDREN DIAGNOSED WITH INCURABLE BLINDNESS USING HEALTH INFORMATION COLLECTED DURING THEIR VISITS TO THE RED CROSS CHILDREN'S HOSPITAL.

1. Background

There is a high burden of blindness in children in lower- and middle-income countries (LMIC). Although vision problems in children account for a relatively low percentage (0.4- 0.5%) of those with visual impairment (Unicef.org, 2022), the prevalence of blindness in children is estimated to be second only to adult cataracts in terms of "blind person-years" (Gilbert & Foster, 2001). Few lower- and middle- income countries (LMICs) possess accurate prevalence data about childhood blindness. Hence the extent of the problem (of childhood blindness) and possible ways to reduce it, is largely unknown (Solebo, Teoh & Rahi, 2017).

According to the IAPB Vision Atlas (IAPB,2022), there were between 300 and 400 blind children per million population globally in 2015. Up to 60% of these children would have died within a year of going blind (Solebo, Teoh & Rahi, 2017; Assefa, Tolessa & Ferede, 2020).
An additional 22 million children suffered from low vision and a further 47 million children had a correctable refractive error causing visual impairment (WHO, 2000).

A higher prevalence of childhood blindness exists in lower- and middle-income countries: Sub- Saharan Africa has an estimated three hundred thousand blind children, while in the Asian region, the number of blind children is approximately one million (Solebo, Teoh & Rahi, 2017). The high prevalence of childhood blindness and visual impairment has been attributed to poor access to primary health care facilities or inadequately trained medical personnel (Gilbert, 2007; Hussain et al., 2019).

2. Study Rationale and Aims and Objectives

The establishment of a childhood blindness register (CBR) is being piloted at the University of Cape Town, South Africa. The aim of the CBR is to create an information resource to help address the problem of fragmented information of children diagnoses with incurable blindness. The loss to follow-up of children with disabilities is high and it is anticipated that this may be more common in blind children.

Some of the activities include obtaining stakeholder buy-in, exploring the policy environment related to childhood blindness, and characterising the causes of childhood blindness. Analysis of the causes of blindness in children will provide information that will be useful for planning, development, and implementation of health, education and social services for blind children. Children diagnosed with irreversible blindness will be registered on the CBR and their information updated through service users' inputs. The CBR will provide ready data that can be analysed any time for interpretation and use. The CBR will allow health, educational, social development and civil society users to access and updated the data which in turn will help to include blind children in necessary service delivery.

Red Cross War Memorial Children's Hospital (RXH) in Cape Town is the major tertiary reference hospital for childhood blindness in the Western Cape Province of South Africa. Over 5000 children attend the hospital every year with over 1000 sight restoring operations performed yearly. A further 3800 children benefit from medical, surgical and laser treatments and rehabilitation to improve their visual function.

Children who have been diagnosed with irreversible blindness are referred to educational and social development services. There are several gaps in what is known about the effectiveness of uptake of these services amongst blind children.

To ensure up to date information in the registry, a case verification step will be required, during which blind children will be followed-up to monitor their status of visual function, their participation in educational activities and the social support they benefit from.

After diagnosis of incurable blindness, it is important to retain connection with the child and their caregiver, hereafter referred to as "key informant", to ensure that accessing

health services, social services and education facilities is continued and the child remains connected. The health information obtained from the children and their key informants is an essential link in the contactability with the child and their key informant. It is also important that this information is correct and accurate, as the means of contacting the child and key informant depends on this. This also allows for accessibility to the necessary information of the child and key informant in an efficient manner when required to do so in the future. This can also be beneficial in identifying some of the challenges faced by children and key informants in accessing support services, that will help with determining strategies to address them.

At registration, patients' demographic information is entered into the CliniCom health information system at RXH for the purpose of operational and financial management. At the eye department, a patient file is created, and further information is generated during interview with the key informant and patient, and the subsequent examination, assessment, and treatment of the patient. This information (clinical, surgical, treatment and management) is appended to the file. The appropriate referral procedures are followed, which in the case of children with irreversible blindness, may include referral to special institutions for education and rehabilitation.

Children diagnosed with incurable blindness may not necessarily return to the eye department for treatment, but may have other health, education, or social development service needs. Because of various factors, including accessibility, information, cultural and economic barriers, many blind children do not make use of the services they need. Many key informants may not be aware of recent developments in social service policy and availability which can benefit the blind children in their care. The low uptake of early childhood development services further justifies the need to conduct proactive follow-up of children diagnosed with incurable blindness. It is therefore essential to have up-to-date, reliable information about how to contact these children, through their key informants.

This study aims to determine the accuracy of available contact information of a cohort of children diagnosed with incurable blindness from 1 January 2011 to 31 December 2020 at RXH and identify strategies that ensure that contact information of key informants is up-to- date and useful for follow-up.

The objectives of the study are:

a) To determine the accuracy of the contact information of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
b) To identify the reasons for inaccurate contact information of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
c) To determine the loss to follow-up rate due to inaccurate contact information of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
d) To determine the rate of uptake of health services of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
e) To determine the rate of uptake of education services of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
f) To determine the rate of uptake of social development services of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.

The main activities of the study are:

- To obtain approval from RXH to access files of referred children to collect contact information about the children diagnosed with blindness between 2011 and 2020.
- To obtain ethical approval for the study from the Western Cape Health Department and the UCT Human Research Ethics Committee.
- To contact key informants of referred blind children and obtain relevant information
- To contact selected referral institutions to verify information related to uptake of health, education and social development services.
- To analyse data, interpret and report findings

The study's findings will provide critical information to be used in designing the registry database, and approach to be adopted for the case verification protocol. In addition, there will be availability of baseline data to be used for engagement with broader stakeholder groups to formulate policy tools for advocacy to support the development and implementation of a provincial CBR.

3. Methodology

The following definitions will be used for this study:

Blindness *according to WHO is a visual acuity of less than 3/60 in the better eye.*

Vision loss: *a term used to indicate any degree of reduced vision, including blindness. Childhood: persons aged up to 14 years. The RXH data includes only children aged up to 10 years.*

Primary key informants*:* *the children diagnosed with blindness*

Secondary key informants*:* *parents, family members who are caregivers of the children in the study*

Tertiary key informants: *service providers like health care workers, social workers, teachers and others who provide supporting information to the follow-up teams.*

Stakeholders: *role-players interested in and involved in the care, development and progress of children affected by vision loss.*

Study design

The study design is that of a quantitative, cross-sectional survey, obtaining information, including observations, measurements, and views of key informants about children who have been diagnosed with incurable blindness.

Population and sampling

The target population is all respondents who can provide information about the whereabouts, abilities and progress of children who have been diagnosed with incurable blindness at RXH. The study sample comprises those associated with the children diagnosed between January 2011 and December 2020.

Data collection methods

A list of all children diagnosed with incurable blindness between January 2011 and December 2020 has been created as part of a study to characterise the causes of blindness in children as diagnosed at RXH. Over this period, a total of 186 children,

diagnosed with incurable blindness, were referred to Athlone School for the Blind in Cape Town.

The demographics and clinical data will be captured into a specially designed, closed, secure access database, to create the electronic resource to be used for epidemiological analysis. At the time of this research, the database is only accessible through local area network (VPN) access by the Principal Investigators of the bigger CBR project (Prof Christopher Tinley and Dr Deon Minnies), the protocol of which is currently being developed. The electronic database is currently being tested to ensure accurate data collection, analysis and enquiry. The database access will be expanded to allow read-only access to co-investigators of the causes characterization study, and this one, the "follow-up" study. Following completion and ethical approval of the bigger CBR study, ophthalmologists at RXH will be able to register newly diagnosed blind children in the database

After having obtained the necessary ethical approvals and permission from RXH, we will obtain contact information of these children from their hospital files and make telephone calls to obtain key information that will help to answer the research question.

A specially designed questionnaire will be used, comprising mainly closed questions, but also two open questions for comments and feedback from respondents.
The researcher will contact the caregiver by telephone and address the respondent in their most preferred language (English or Xhosa). A suitable translated version of the consent form will be used as a transcript for the consent-taking.

The following data will be collected:

PRIMARY KEY INFORMANT		**SOURCE**
Name 1,2,3	Text [15, 15, 15]	Already available
Address 1,2,3	Text [15, 15, 5]	
Date of birth	Date	
Place of birth	Date	
Gender	Text [6]	
File number	Number [15]	
PKI verified	Logical	This study
PKI comment 1,2,3	Text [30, 30, 30]	
FOLLOW-UP DETAILS		
Date of follow-up	Date	Already available
Main pathologies RE 1,2,3	Text [15, 15, 15]	
Main pathologies LE 1,2,3	Text [15, 15, 15]	
Other disabilities 1,2,3,4,5[1]	Text [10, 10, 10, 10, 10]	
Wearing spectacles?	Logical	This study
Attending school?	Logical	
Type of school	Text [15]	
Comment about school	Text [30]	
Receiving child grant?	Logical	
Receiving disability grant?	Logical	
Comment about grant	Text [30]	
Last health support	Text [15]	
Last social support	Text [15]	
Last other support	Text [15]	
Comment about support	Text [30]	
Recently attended health service?	Logical	
Comment about health service	Text [30]	
Recently hospitalised?	Logical	
Comment about hospitalization	Text [30]	
Recently underwent operation?	Logical	
Comment about operation	Text [30]	
SECONDARY KEY INFORMANT		
Receiving child grant?	Logical	YES / NO
Name 1,2,3	Text [15, 15, 15]	Surname, name1, name2
Address 1,2,3	Text [15, 15, 5]	Street address, area, town
Date of birth	Date	Format dd/mm/yyyy
Informed consent?	Logical	YES / NO
Occupation	Text [15]	Could be in a list
Gender	Text [6]	Male / Female / Other
Relation to PKI	Text [15]	Could be in a list
Contact number 1,2	Number [10]	Format ###-###-####
Comment 1, 2, 3	Text [30, 30, 30]	

The following results will be determined:

Demographic disaggregation (age, sex, home language) of blind children
Demographic disaggregation of primary caregivers (age, sex, grants received)
Proportion of successful connections
Proportion of willing respondents
Proportion of children located
Proportion of children verified
Tabulations of children's visual and disability outcomes
Proportion of children with health interactions
Proportion of children at school plus types
Proportion of children receiving grants plus types
Proportion of children receiving support disaggregated
Tabulations of secondary key informants' demographics, relations and occupation
Views, challenges and achievements as reported

Analysis and interpretation

The data will be analysed using simple statistical methods, with cross-tabulations for selected variables, and figures where appropriate. The narrative comments will be quantitatively analysed and summarised in tables. No identifiable information (names, addresses, telephone numbers) of children or their caregivers will be used in the analysis of the data.

Ethics and consent

Ethical clearance will be obtained from RXH to access the contact details of the caregivers of the children diagnosed with incurable blindness.
As this is a study towards a mini dissertation for a Master of Public Health degree at the University of Cape Town, ethics approval will also be sought from the UCT Human Research Ethics Committee.

A consent form will be used to guide the researcher in obtaining informed consent from the respondent. This will explain the aim and purpose of the study, what will be expected from the respondent, the risks and benefits of the study and address issues of confidentiality, autonomy and voluntary participation. The consent form will be available in the three main languages spoken in the Western Cape

Province of South Africa, namely, Afrikaans, English and Xhosa.

Assumptions and limitations

It is assumed that respondents will be available, willing and able to answer the questions of the researcher, and that only one interaction will be required. It is also assumed that the information obtained is the truth.

The main limitation of the study is that there will be no means of verifying the information provided. Also, the list of children diagnosed with incurable blindness at RXH from 2011 to 2020 may not be totally inclusive.

Significance of the study

The findings will be used to inform the bigger CBR project on approaches to design and implement protocols for use in the registry's database, the case verification step, and engagement with stakeholders. From the findings it will also be possible to suggest strategies to reduce the rate off loss to follow up. Overall, the study will provide baseline data to support applications for approval to conduct the CBR study, and obtain funding for implementation of the study, advocacy and stakeholder mobilization.

4. References

1. Assefa, N. L., Tolessa, K. G., & Ferede, A. T. 2020. Knowledge of Childhood Blindness and Associated Factors Among Parents or Guardians in Maksegnit Town, Northwest Ethiopia. Clinical optometry, 12, 175–182.

2. Gilbert C. 2007. Changing challenges in the control of blindness in children. Eye (London, England), 21(10), 1338–1343.

3. Gilbert, C., & Foster, A. 2001. Childhood blindness in the context of VISION 2020--the right to sight. Bulletin of the World Health Organization, 79(3), 227–232.

4. Gilbert, C., & Foster, A. 2001. Blindness in children: control priorities and research opportunities. The British journal of ophthalmology, 85(9), 1025–1027.

5. Hussain, A., Ferdoush, J., Mashreky, S. R., Rahman, A., Ferdausi, N., & Dalal, K. 2019. Epidemiology of childhood blindness: A community-based study in Bangladesh. PloS one, 14(6), e0211991.

6. IAPB Vision Atlas. 2022. Retrieved from iapb.org/: https://www.iapb.org/learn/vision- atlas/

7. Solebo, A. L., Teoh, L., & Rahi, J. 2017. Epidemiology of blindness in children. Archives of disease in childhood, 102(9), 853–857.

8. Unicef, 2022. Retrieved from data.unicef.org: https://data.unicef.org/topic/child-disability/overview/

9. World Health Organization. Blindness and Deafness Unit & International Agency for the Prevention of Blindness. 2000. Preventing blindness in children: report of a WHO/IAPB scientific meeting, Hyderabad, India, 13-17 April 1999. World Health Organization.

APPENDIX A: CONSENT FORM

PARTICIPANT'S INFORMATION PAGE

Dear Sir/ Madam,

My name is Noluthando Mjwana, and I am a student at the University of Cape Town. I am currently doing my Master of Public Health degree in Community Eye Health.

My research project and topic of interest is aimed at determining the uptake of social support services provided to children who have an irreversible blindness as well as factors that hinder or help their follow up process in a LMIC setting.

I would like to request your permission and to be granted consent by you to take part in this research project.

This research project, in the form of a telephonic interview will be conducted telephonically and at your convenience.

I will ask you questions about the child who you are taking care of.

Should you have any further questions on the research, please feel free to ask for any further clarification as it is very important that you are able to understand what it entails.

Participation in this study is entirely voluntary, and therefore you may choose whether to participate or not. Choosing to not participate will not affect you in any way negatively. You are also free to stop me at any time during the session should you not wish to continue any further.

Confidentiality is fully assured, and your names will not be published in any form and only the research team will have access to the results.

CONSENT FORM

A PRELIMINARY INVESTIGATION TO DETERMINE THE UPTAKE OF SOCIAL SUPPORT SERVICES AND FACTORS THAT HINDER OR HELP WITH FOLLOWING-UP OF CHILDREN DIAGNOSED WITH INCURABLE BLINDNESS IN A LOW- AND MIDDLE- INCOME SETTING.

Do you give permission and grant consent to participate in the research?

Yes [ ] No [ ]

Do you confirm that you understand the information that was read to you and have had an opportunity to ask questions?

Yes [ ] No [ ]

Do you understand that your participation in this study is voluntary, and that you are free to withdraw at any time, without giving reason.

Yes [ ] No [ ]

File no:_____ Date:_____

Researcher Signature: _____ Date: _____

APPENDIX B: QUESTIONNAIRE

PRIMARY KEY INFORMANT DETAILS

1. Name: ……
2. Address: ……
3. Date of birth: ……
4. Gender: M [ ] F [ ] Other [ ]
5. File no: ……
6. Is the Primary Key Informant verified? Y [ ] N [ ]
7. Comments: ……

FOLLOW UP DETAILS

8. Follow up date: ……
9. Main pathologies:
    a. RE: ……
    b. LE: ……
10. Does the child wear spectacles? Y [ ] N [ ]
11. Does the child attend school? Y [ ] N [ ]
12. What type of school do you attend?
13. Mainstream [ ]
14. Special school for the blind [ ]
15. Other [ ] (specify) ……
16. Does the child receive a child grant? Y [ ] N [ ]
17. Does the child receive disability grant? Y [ ] N [ ]
18. Do you have any comment about grant? Y [ ] N [ ]

19. When was the child's last health support given? ……..

20. When was the child's last social support given? ……..

21. When was the child's last other support given? ……..

22. Do you have any comment about the support received?

……..

23. Has the child recently attended any health service? Y [ ] N [ ]

24. Is there any comment about the health service you attended? Y [ ] N [ ]

……

25. Has the child recently been hospitalised? Y [ ] N [ ]

26. What is your comment about your hospitalization?

……..

27. Did the child recently undergo an operation? Y [ ] N [ ]

28. What is your comment about the operation?

……..

SECONDARY KEY INFORMANT DETAILS

29. Are you receiving any child grant? Y [ ] N [ ]

30. Name ……

31. Address: ……..

32. Contact no: …….

33. What is your occupation? ……..

34. What is your gender? M [ ] F [ ] Other [ ]

35. What is you relation to the Primary Key Informant?

……

36. Is there any other comment? Y [ ] N [ ]

……

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/home/human-research-ethics

14 December 2022

HREC REF: 789/2022

Dr D Minnies
Division of Ophthalmology
H-53 OMB
Email: d.minnies@uct.ac.za
Student: MJWNOL001@myuct.ac.za

Dear Dr Minnies

PROJECT TITLE: A PRELIMINARY INVESTIGATION TO DETERMINE THE UPTAKE OF SOCIAL SUPPORT SERVICES AND FACTORS THAT HINDER OR HELP WITH FOLLOWING-UP OF CHILDREN DIAGNOSED WITH INCURABLE BLINDNESS IN A LOW- AND MIDDLE- INCOME SETTING-
(MASTERS CANDIDATE-MISS NOLUTHANDO MJWANA)

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study, subject to adding the HREC contact details to the informed consent document.

Approval is granted for one year until the 30 December 2023.

Please submit a progress form, using the standardised Annual Report Form (FHS016) if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Miss Noluthando Mjwana will also be involved in this study.

Please quote the HREC REF 789/2022 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Form FHS006: Protocol Amendment

HREC office use only (FWA00001637; IRB00001938)			
☑ Approved	☑ Type of review: Expedited	☐ Full committee	
This serves as notification that all changes and documentation described below are approved.			
Signature HREC Chairperson / Designee		Date	16/11/2023

Note: All **Major** amendments must include a **Cover Letter** and a local **PI Synopsis** justifying the changes for the amendment. Please note that incomplete amendment submissions will not be reviewed.

HUMAN RESEARCH ETHICS COMMITTEE
- 2 NOV 2023
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za with subject line: FHS006 + (HREC Reference number).

The latest forms are found on our website.

http://www.health.uct.ac.za/fhs/research/humanethics/forms

Please also clarify your plan for research-related activities during COVID-19 lockdown.

Comments from the HREC to the Principal Investigator:
Thank you for the response, received 16/11/2023
Note: The approval of this protocol amendment does not grant annual approval. Please complete the FHS016 / FHS017 form for annual approval at least one month before study expiration.

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	25 October 2023		
HREC REF Number	HREC REF 789 /2022		
Protocol Title	A preliminary investigation to determine the uptake of social support services and factors that hinder or help with the follow up of children diagnosed with incurable blindness in low- and middle-income setting.		
Protocol Number (if applicable)			
Principal Investigator	Deon Minnies		
Department / Office Internal Mail Address	Division of Ophthalmology, Department of Surgery		
1.1 Is this a major or a minor amendment? (see FHS006hlp) Major (tick box) Minor (tick box)		☐ Major	☐ Minor ✓

1.2 Does this protocol receive US Federal funding?	☐ Yes	☐ No ✓
1.3 If the amendment is a major amendment and receives US Federal Funding, does the amendment require full committee approval? **Note:** Any protocol amendments for **Full Committee Review** MUST be submitted on the monthly HREC submission dates. (Please email an electronic copy to hrec-enquiries@uct.ac.za)	☐ Yes	☐ No ✓
1.4 Did the initial study require UCT No-Fault Insurance	☐ Yes	☐ No ✓

2. List of Proposed Amendments with Revised Version Numbers and Dates

Please itemise on the page below, all amendments with revised version numbers and dates, which need approval.
This page will be detached, signed and returned to the PI as notification of approval. Please add extra pages if necessary.

Title change

Elaboration of rationale

Revised aim

3. Protocol status (tick ✓)

☐	Open to enrolment
☐	No participants have been enrolled
	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
✓☐	Research-related activities are complete, data analysis only

4. Proposed changes will affect: (tick ✓ all the categories that apply)

Protocol	
☐	Study objectives, design (including investigator's brochure, clinical activities, study length)
☐	Study instruments, questionnaires, interview schedules
☐	Sample size
☐	Recruitment methods
☐	Eligibility criteria (inclusion and exclusion criteria)
☐	Drug/device (composition, amount, schedule, route of administration, combination with other drugs/devices, safety information)

☐	Data collection/ analysis
☐	Principal Investigator. (Please attach revised conflict of interest and PI declaration statements. Refer: sections 7 and 8.4 in the New Protocol Application Form FHS013)
☐	Consent form and information sheet
☐	Recruitment materials (e.g. advertisements)
☐	Administrative (e.g. change in sponsor's name, change in contact information)
☐	Other. Please specify:

**Note: Amendment changes involving study length, sample size, additional sites and eligibility criteria (i.e. inclusion of minors and /or pregnant woman) need to be declared to the Insurance office. Please liaise via fhs.sponsorship@uct.ac.za regarding the required documentation and information to be submitted to obtain an updated UCT No-fault Insurance Certificate- it should be included herewith*

4.1 In your opinion, will there be any **increase** in risk, discomfort or inconvenience to participants?	☐ Yes	☐ No ✓
If yes, please provide a detailed justification/explanation:		

4.2 What follow-up action do you propose for participants who are already enrolled in the study?	
☐	Inform current participants as soon as possible
☐	Re-consent current participants with revised consent/assent forms (append)
☐✓	No action required
☐	Other. Please describe:

5. Detailed description of the change(s)

Please attach, for each amendment, a summary of all changes which clearly indicates:

i. Old wording (e.g. ~~strikethrough~~ text, CHANGED FROM and CHANGED TO)

ii. New wording (e.g. *italicized*, **bold**, tracked)

iii. Detailed rationale/ justification/ explanation for each change

6. Ethics Review for Amendment Levy – cost including vat

Amendment Review Costs including VAT

Please tick amount to be billed:

Submission Type	*Description*	*New fee (Vat Incl.)*	*tick ✓*
Research funded solely from UCT departmental/ divisional/group budget	Major/ Minor Amendments	**R0,00**	☐
Non-sponsored student research for degree purposes at UCT/Other Universities & Colleges	Major/ Minor Amendments	**R0,00**	✓☐
Protocol amendment - Major (FHS006 Form)	Clinical Trial & International Grant Funded Research - Any changes to the protocol that requires Full Committee review	**R8 000.00**	☐
Protocol amendment - Major (FHS006 Form)	Clinical Trial & International Grant Funded Research - Any change to the protocol that requires Expedited review that does not require Full Committee Review	**R5 000,00**	☐
Protocol amendment - Minor (FHS006 Form)	Clinical Trial & International Grant Funded Research - Minor amendments, administrative changes that do not affect study design e.g. changes to informed consent form, changes in study staff, etc.	**R2 250,00**	☐
Protocol amendment - Major (FHS006 Form)	National grant funded research - Any change to the protocol that requires Full Committee review	**R7 000,00**	☐
Protocol amendment - Major (FHS006 Form)	National grant funded research - Any change to the protocol that requires Expedited review that does not require Full Committee review	**R2 500,00**	☐
Protocol amendment - Minor (FHS006 Form)	National grant funded research - Minor amendments, administrative changes that do not affect study design e.g. changes to informed consent form, changes in study staff, etc.	**R1 000,00**	☐

NB: Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from these charges.

Please provide details for Invoicing, either complete section 1 or 2 :

1. Invoice billing – Directly to Sponsor

Sponsor's name	
Billing Address of Sponsor:	
Vat Number:	
Contact person:	
Telephone number:	
Email Address:	

2. Internal Journal Billing:

Fund Number:	
Cost Centre Number:	

Account Holder Name:	
Division of Account Holder:	

7. Amendment Submission checklist (tick ✓)

7.1 Please tick that all the documents are attached before submitting to the HREC. NB: Incomplete submissions will not be processed	
✓☐	Latest FHS006 form completed with all sections completed as per our website
✓☐	Cover Letter
✓☐	PI Justification/ Summary for the reasons for the amendment
✓☐	Protocol - Track changes & Clean Copy (where necessary)
☐	Informed Consent Forms (ICF), if applicable (Any changes made to ICF tracked & clean copy)
☐	Any other additional documentation in support of amendment
☐	Updated no fault insurance certificate (if applicable)

Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za with subject line: FHS006 + (HREC Reference number). The latest forms are found on our website.

8. Signature

My signature certifies that I will maintain the anonymity and/ or confidentiality of information collected in this research. If at any time I want to share or re-use the information for purposes other than those disclosed in the original approval, I will seek further approval from the HREC.

Signature of PI	Signed by candidate	Date	25 October 2023

Western Cape Government

DR M SALIE
Acting Manager: Medical Services
Red Cross War Memorial Children's Hospital

Email: Ellen.Thomas@westerncape.gov.za
Tel: +27 21 658 5383

Date: 02 February 2023

Ms N Mjwana
Ophthalmology

Dear Ms Mjwana

RESEARCH: RXH: RCC 360 / WC_202212_022

PROJECT TITLE: A Preliminary Investigation to determine the uptake of Social Support Services and factors that hinder or help with following-up of children diagnosed with incurable blindness in a low- and middle- income setting.

Thank you for submitting your study to the Red Cross War Memorial Children's Hospital Research Committee for review.

It is a pleasure to inform you that the Red Cross Children's Hospital Research Committee has formally approved your application to conduct above-mentioned study.

Approval is granted for one year until **30 December 2023** as per your ethics approval.

Kindly submit a renewal request if your study continues beyond the approval period with a progress report. If the study is completed within the approval period, please inform the committee. A copy of your final document to be submitted after completion of your project.

Kindly quote the reference **RXH: RCC 360 / WC_202212_022** in all your correspondence.

Yours sincerely,

Signed by candidate

DR M SALIE
ACTING MANAGER: MEDICAL SERVICES

PART B
Literature review

TABLE OF CONTENTS

Introduction

Childhood blindness and visual impairment is a major cause of psychosocio-economic problems in children and their families (Solebo & Rahi, 2014). In most cases, these negative effects usually continue into adulthood, affecting their quality of life through their inability to be economically active, productive and socially interactive (Mezer et al., 2015; Heijthuijsen et al., 2013). In poor communities, families of children with visual impairment carry additional burdens of high cost for health and educational services.

Due to this negative impact of childhood visual impairment and blindness, it has been prioritized by the VISION 2020 initiative whose aim was the elimination of avoidable blindness by the year 2020 (WHO, 2021). The Universal Eye Health strategy for eye care, "the Global eye health action plan: 2014–2019" and the InSight 2030 strategy also emphasized the importance of determining the burden of eye diseases and the elimination of avoidable visual impairments and blindness in children (Heijthuijsen et al., 2013).

Reducing the occurrence of children having vision difficulties has the benefit of restoring to a child a quality of life of up to ten times that of restoring the sight of an adult with blinding cataract (Gilbert & Foster, 2001). However, the processes of identifying, referral, diagnosis and treatment / rehabilitation of children with visual impairment are hampered by many challenges, including lack of resources, skills, equipment and supplies (Gilbert & Foster, 2001; Hussain et al., 2019). Structural, ethical and policy issues further hamper the planning and implementation of effective intervention strategies (Solebo & Rahi, 2014).

Causes and aetiology of childhood blindness

Globally, it has been reported that, in low and middle-income countries, the main causes of blindness in children are retinal disorders, glaucoma, corneal ulcers due to vitamin A deficiency as well as cataract, (Heijthuijsen et al., 2013; Santos-Bueso et al., 2015).

The main anatomical sites of abnormalities are the lens, the cornea, and the globe (Hussain et al., 2019; Asferaw, Woodruff, & Gilbert, 2017).

It has been stated that many of the reasons for children being blind or visually impaired are avoidable, i.e., can be prevented and treated, such as Vitamin A deficiency, cataract or uncorrected refractive errors (Gilbert & Foster, 2001).

According to Kemmanu et al., (2016), the aetiology of childhood blindness is influenced by various factors such as the socioeconomic state of the country and whether the services can be easily accessible. In studies conducted in some LMIC settings such as Ethiopia and Bangladesh, it was determined that, the aetiology of childhood blindness is mainly due to childhood, hereditary, intrauterine, and perinatal factors (Hussain et al., 2019; Asferaw, Woodruff, & Gilbert, 2017).

Although most of the causes of childhood blindness are avoidable, a large proportion of children with eye problems become irreversibly blind. Those irreversibly blind are mostly due to optic nerve, congenital eye anomalies and retinal dystrophies (Muhit et al., 2018).

Non-clinical reasons for causes of childhood blindness

The non-clinical reasons for children in LMICs having to live with avoidable blindness include social, technological, and political factors (Koay et al., 2015). Central to this is the lack of up-to-date epidemiological data of childhood blindness and visual impairment to inform the design and implementation of suitable intervention strategies. This is because of lack of resources including suitably trained staff and equipment as well as limited facilities that offer eyecare services (Gilbert, 2007).

Incurable blindness in children requires an approach to ensure that their quality of life is improved, and they are also able to develop socially. The involvement and support of family members is critical in ensuring that the child can live with the disease. Part of the support means that family members are trained and provided with counselling on what the child's disability is and how to deal with a blind child as well as the provision of access to facilities that offer services for their children. This was supported by Gladstone et al, (2017) in a study conducted to analyse care and support for visually impaired children.

Once blindness becomes irreversible, the blind child and caregivers must be trained to manage the condition. This can be achieved by providing rehabilitative support services and interventions at an available tertiary eyecare facility. This training must be provided by a multi-disciplinary team of well-trained specialists to teach the child mobility and to be functional to support their development and improve quality of life (Solebo & Rahi, 2014).

Frequently, the blind children and their families find it difficult to access information,

support and the services they need. It therefore is important that health, disability and social services are involved to act as links between the service providers such as schools and rehabilitation centres and the families to provide the necessary referral to meet the needs of the families (Gilbert, 2007; Rahi et al, 2004).

Epidemiological studies to determine the magnitude and distribution of blindness in children are challenging. Few countries have up-to-date epidemiological data of the magnitude, distribution and causes of childhood blindness (Solebo, Teoh & Rahi, 2017). This paucity of accurate data poses difficulty for effective planning of suitable interventions. One of the reasons for this is the difficulty of conducting prevalence studies about blindness and visual impairment in children. In many low- and middle-income countries (LMICs), the prevalence of childhood blindness and visual impairment is neither well determined nor properly measured (Gilbert & Foster, 2001). Unlike Rapid Assessment of Avoidable Blindness (RAAB) surveys, which provide relatively easy methodology for conducting prevalence surveys in people aged 50 years and above, blindness surveys in children require a very large sample size (Wadhwani et al., 2020) because the prevalence is much lower. Furthermore, children spend much of their time away from home, and blind and visually impaired children, if they are at home, they may be isolated or hidden from the community, because of difficulty in mobility and / or stigma (Baxter et al., 2014; Kulkarni et al., 2022

Obtaining data about childhood blindness prevalence and causes from blind school surveys cannot provide reliable prevalence data, because only those children in schools are included (Gilbert & Lepvrier-Chomette, 2016). Conducting these surveys in mainstream schools can produce inaccurate data, because of similar reasons.

The Key Informant Method

Recently, the Key Informant Method (KIM) of determining prevalence and causes of blindness has shown that it is possible to collect accurate population-based data about blindness from caregivers of blind children. In many settings, these have become a reference methodology (Gogate et al., 2014; Kilangalanga et al., 2020). However, the KIM approach has some limitations, primarily related to the need to comprehensively identify and interview key informants (Gogate et al., 2014).

Barriers to access to care for children with blindness

According to Alrasheed, (2021), barriers to eye care are broadly defined as factors that affect people from accessing services such as healthcare, which negatively influences both services delivered and access. Obstacles to access eye care services for children are wide-ranging and encompass factors that hinder children from obtaining these services, ultimately leading to negative consequences for both service distribution and access (Alrasheed, Mohamed, & Alluwimi, 2024).

The main barriers to accessing paediatric eye care services in Africa were non-availability, non-accessibility, and non-affordability, lack of knowledge, negative attitudes of parents and primary health system (Alrasheed, 2021).

This is further confirmed in a report contained in Pawar et al, (2023), where in explaining health care seeking behaviour, it states that it is affected by various factors including education of parents, occupation, marital status, financial status, distance, regional beliefs and treatment, family-related problems, accessibility, and affordability
In a systematic review conducted by (Alrasheed, Mohamed, & Alluwimi, 2024) it indicated that, the barriers to accessing eyecare services were the awareness, practices and attitudes of the community towards childhood.

The significance of a Childhood Blindness Registry

To conclude, it is proposed that a Childhood Blindness Registry would help to build a characterization of the magnitude, distribution and causes of blindness-causing conditions in children, provide information for interdisciplinary management of children affected by blindness and severe visual impairment.

The Community Eye Health Institute at the University of Cape Town (UCT-CEHI), South Africa is currently piloting the establishment of a Childhood Blindness Registry (CBR project) in the Western Cape Province of South Africa, by exploring the feasibility, value and suitability of such in relation to the relevant structural, ethical and policy frameworks. Feasibility describes how easy or difficult it is to do something, and feasibility of health interventions as defined in nurse.com, refers to the practicality and adequacy of the logistics required for

delivering interventions (Nurse Key, 2021).

In a feasibility study for Environmental Health registry, several factors, including reasonable timeliness, sufficient funding and appropriate funding were regarded as points for consideration before establishing a registry (Solomon et al., 1991)**.**

Overall, the feasibility of a registry can be conceived as a construct related to the physical structure, function, data and user interface of such a registry. Some of the key aspects that determine feasibility are the ability to address exposure / health concerns of a population, having reasonable timeliness, sufficient funding, appropriate staffing, adequate communications capabilities with registrants, and ability to collect the necessary information.

In Solomon et al., Bellows' definition of a registry is cited as a system of recording, frequently used in the general field of public health, which serves as a device for the administration of programs concerned with the long-term care, follow-up or observation of individual cases (Solomon et al., 1991). The same authors define a registry as a database of identifiable people containing a clearly defined set of health and demographic data, collected for a specific public health purpose, while Kodra et al., describes a registry as an organised system, highlighting the prospective characteristic of its design (Kodra et al., 2018).

In describing the purpose or function of a registry, various authors describe it as, systems that can generally be used to monitor the quality of care and provide relevant feedback, description of treatment plans, observation of the natural course of diseases, monitoring of clinical safety, assessment of disease burden, health outcomes, and costs of the diseases (Pringsheim et al., 2013), while Antao et al., (2015), states that it is used to generate relevant statistics about the group of registered people.

In a feasibility study for a dementia registry conducted in Ireland, factors such as provision of information that is accurate and comprehensive were regarded as beneficial as this would enhance knowledge and awareness on dementia as well as inform public health policy (Hopper et al., 2016).

According to Adebusoye et al. (2022), a multi-country study has demonstrated that the availability of clinical registries indeed improves health outcomes, increases the value of healthcare, and lower healthcare costs in the long run by translating data to guidelines and enabling clinicians to identify and share best clinical practices. This is supported by Newton & Garner (2002), who state that registers are used to target resources and ensure consistency

and complete coverage.

Proper implementation of a project such as a registry requires that adequate budgeting thereof is provisioned, as this ensures that the registry is sustainability. Different authors agree that important aspects that require consideration when implementing a registry are the cost implications and maintenance (Solomon et al., 1991; Antao et al., 2015).
Feasibility of intervention delivery rests on the interventionists' capacity to provide the intervention, as planned, to the predetermined number of participants, in addition to their availability in an adequate number, the interventionists should be well prepared to provide the intervention with fidelity (Nurse Key, 2021)**.** This speaks to the multidisciplinary team that will ensure that the registry becomes successful, such as medical staff, epidemiologists, health scientists (Antao et al., 2015)

According to vocabulary.com, the ability to access information in an efficient, flexible, and timely fashion is a key element to the success of a public health registry (vocabulary.com, n.d.). Sufficient funding, staffing, communication, and other administrative capabilities are important factors to evaluate before initiating a registry. Funding must be available for the initial operation and the long-term maintenance of the registry. Developing a participatory mechanism is feasible so that the affected population can have input into the registry's design and the research question.

Unambiguous operational definitions of who should and should not be included in the registry are critical for success. They are an essential element of data quality (Solomon et al., 1991). Usability is a design characteristic pertaining to the ease with which people can employ tools and processes to perform goal-related tasks. Included in the characteristics are elements such as ease of learning, recall, satisfaction, and efficiency (Medical Dictionary, 2009).

Blindness registers can be an important tool for public eye health programs and have been used as data sources for population-based research, mostly in the developed world (Aghaji et al., 2017)**.** Such registers for the blind do not exist in low- and middle-income countries. In establishing a childhood blindness registry in South Africa, it is important to know how feasible registries are in their given contexts.

What is CliniCom?

Clinicom is a patient administration system software that is currently used in some public hospitals in South Africa with the intention to integrate patient information.

According to accessgroup.com, a patient administration system (PAS), is an information service providing a foundation to all healthcare. It performs the basic but crucial function of recording non-clinical patient details, such as name, date of birth, and home address, as well as any additional contact details for next of kin in an emergency (Sheasby, 2024)

The benefit of hospitals using CliniCom, is that it enables a patient to have a singular record number in the entire province in any health care setting that is linked to the central Western Cape Patient Master Index (Western Cape Government, 2016). This therefore makes it easy for a healthcare professional to get the patient details and history even if the patient has relocated to another area as long as the patient is linked to this system.

"The system will also provide improved operational reporting and will greatly improve the availability of statistical information regarding patient services." (Western Cape Government, 2016)

In the context of blind children, it has the potential benefit to have up to date information in terms of patient history and accessibility to necessary services. This may also play a role in being able to do follow-up on these children as they would be on the system.

Having all the details in one record throughout this type of network is also helpful when it comes to the establishment of a registry as records of patient history and their progress can be retrieved when required such as for data analysis.

The use of the telephone as a method to conduct interviews

A telephone is one of the mechanisms used for communication purposes among other things. Its use has become so widespread and popular because it is easy to carry around. is easily mobile and convenient. According sanews.gov.za, in the last census conducted in 2022, it is stated that, "The overwhelming majority (92.1%) of households in the country owned a cellphone in working

order, a notable increase from the 3.3% in 2001." (South African Government News Agency, 2023). Having such a large number with cellphones therefore makes it easier to reach them for communication.

In the context of research, it means that it is an effective tool that can be used to collect data Fowler et al, 2019 states that telephone surveys have been a critical source of information for those concerned with public health statistics. This means that with more data received, it will be easier to implement the necessary services or changes to serve the public. In a study focusing on telephone interviews in qualitative study by (Novic, 2008, it states that the advantages of telephone interviews include decreased cost and travel, ability to reach geographically dispersed respondents, ability to oversee interviewers and enhanced interviewer safety.
In stating benefits associated with telephone interviews, (Musselwhite et al, 2007) posits that, using the telephone as a conduit to study participants is less expensive than requiring the participant or the research associate travel for an in-person meeting. These types of interviews do not require any travelling arrangements to be made or venues to conduct interviews but rather these are conducted at the participants' convenience and wherever they feel comfortable responding to a call.

Musselwhite et al (2007), further argues that using the telephone for data collection interviews may also reduce some forms of response bias as the interviewer and participant are potentially less affected by each other's presence, which means that there is less of a chance to try and read the researcher's face for their expressions. Also, the anonymity associated with telephone contact may enable participants to be more forthcoming with their responses. (Musselwhite et al, 2007)

While the telephone method has its great benefits, there is a flipside to it as well. Novic (2008) states that reported drawbacks of telephone interviews include limited telephone coverage in certain areas, lower response rates. This speaks to poor connectivity that may be experienced, resulting in no calls coming through and therefore no data collected which may lead to response bias of data.

Search strategy: PubMed and google scholar were used as search strategies to search for terms for terms. All articles were filtered using English language and year of publication.

Keywords: follow up, childhood / paediatric blindness, visual impairment, low- and middle-income countries

References

1. Alrasheed, S. H. 2021. A systemic review of barriers to accessing paediatric eye care services in African countries. African health sciences, 21(4), 1887–1897

2. Alrasheed, S. H., Mohamed, Z. D., & Alluwimi, M. S. 2024. Childhood visual impairment causes barriers to accessing eye care: A suggested approach for Africa. African journal of primary health care & family medicine, 16(1), e1–e7.

3. Adebusoye, S.O., Jagun, O., Betiku, A.O., Olajide, O.S., & Aham-onyebuchi, U.O. 2022. A review of ophthalmic registries in Africa – The shortage and importance. Rwanda Medical Journal.

4. Aghaji, A. E., Ezegwui, I. R., Shiweobi, J. O., Mamah, C. C., Okoloagu, M. N., & Onwasigwe, E. N. 2017. Using Key Informant Method to Determine the Prevalence and Causes of Childhood Blindness in South-Eastern Nigeria. Ophthalmic epidemiology, 24(6), 401–405.

5. Antao, V. C., Muravov, O. I., Sapp, J., 2nd, Larson, T. C., Pallos, L. L., Sanchez, M. E., Williamson, G. D., & Horton, D. K. 2015. Considerations Before Establishing an Environmental Health Registry. American journal of public health, 105(8), 1543–1551.

6. Asferaw, M., Woodruff, G., & Gilbert, C. 2017. Causes of severe visual impairment and blindness in students in schools for the blind in Northwest Ethiopia. BMJ global health, 2(2), e000264.

7. Assefa, N. L., Tolessa, K. G., & Ferede, A. T. 2020. Knowledge of Childhood Blindness and Associated Factors Among Parents or Guardians in Maksegnit Town, Northwest Ethiopia. Clinical optometry, 12, 175–182.

8. Baxter, S. L., Wormald, R. P., Musa, J. M., & Patel, D. 2014. Blindness Registers as Epidemiological Tools for Public Health Planning: A Case Study in Belize. Epidemiology Research International, 1-8.

9. Cooper H, Hedges LV, Valentine JC. 2019. The handbook of research synthesis and meta-analysis. Russell Sage Foundation.

10. Gilbert, C. E., & Lepvrier-Chomette, N. 2016. Gender Inequalities in Surgery for Bilateral Cataract among Children in Low-Income Countries: A Systematic Review. Ophthalmology, 123(6), 1245–1251.

11. Gilbert C. 2007. Changing challenges in the control of blindness in children. Eye (London, England), 21(10), 1338–1343.

12. Gilbert, C., & Foster, A. 2001. Childhood blindness in the context of VISION 2020--the right to sight. Bulletin of the World Health Organization, 79(3), 227–232.

13. Gilbert, C., & Foster, A. 2001. Blindness in children: control priorities and research opportunities. The British journal of ophthalmology, 85(9), 1025–1027.

14. Gladstone, M., McLinden, M., Douglas, G., Jolley, E., Schmidt, E., Chimoyo, J., Magombo, H., & Lynch, P. 2017. 'Maybe I will give some help…. maybe not to help the eyes but different help': an analysis of care and support of children with visual impairment in community settings in Malawi. Child: care, health and development, 43(4), 608–620.

15. Gogate, P., Patil, S., Kulkarni, A., Mahadik, A., Tamboli, R., Mane, R., Borah, R., & Rao, G.V. 2014. Barriers to follow-up for pediatric cataract surgery in Maharashtra, India: how regular follow-up is important for good outcome. The Miraj Pediatric Cataract Study II. Indian journal of ophthalmology, 62(3), 327–332.

16. Heijthuijsen, A. A., Beunders, V. A., Jiawan, D., de Mesquita-Voigt, A. M., Pawiroredjo, J., Mourits, M., Tanck, M., Verhoeff, J., & Saeed, P. 201). Causes of severe visual impairment and blindness in children in the Republic of Suriname. The British journal of ophthalmology, 97(7), 812–815.

17. Hopper, L., Hughes, S., Burke, T., & Irving, K. 2016. A National Dementia Registry For

Ireland: A Feasibility Study. 10.13140/RG.2.2.15752.83203.

18. Hussain, A., Ferdoush, J., Mashreky, S. R., Rahman, A., Ferdausi, N., & Dalal, K. 2019. Epidemiology of childhood blindness: A community-based study in Bangladesh. PloS one, 14(6), e0211991.

19. IAPB Vision Atlas. 2022. Retrieved from iapb.org/: https://www.iapb.org/learn/vision-atlas/

20. 1. Kemmanu, V., Hegde, K., Giliyar, S. K., Shetty, B. K., Kumaramanickavel, G., & McCarty, C. A. 2016. Prevalence of Childhood Blindness and Ocular Morbidity in a Rural Pediatric Population in Southern India: The Pavagada Pediatric Eye Disease Study-1. Ophthalmic epidemiology, 23(3), 185–192.

21. Kilangalanga, N. J., Nsiangani, L. N., Dilu, A. A., Moanda, K. A., Ilunga, M. J., Makwanga, M. E., Stahnke, T., & Guthoff, R. 2020. Epidemiology of Childhood Blindness and Low Vision in Kinshasa-Democratic Republic of the Congo. Ophthalmic epidemiology, 27(1), 45–51.

22. Koay, C. L., Patel, D. K., Tajunisah, I., Subrayan, V., & Lansingh, V. C. 2015. A comparative analysis of avoidable causes of childhood blindness in Malaysia with low income, middle income and high-income countries. International ophthalmology, 35(2), 201–207.

23. Kodra, Y., Weinbach, J., Posada-de-la-Paz, M., Coi, A., Lemonnier, S. L., van Enckevort, D., Roos, M., Jacobsen, A., Cornet, R., Ahmed, S. F., Bros-Facer, V., Popa, V., Van Meel, M., Renault, D., von Gizycki, R., Santoro, M., Landais, P., Torreri, P., Carta, C., Mascalzoni, D., Taruscio, D. 2018. Recommendations for Improving the Quality of Rare Disease Registries. International journal of environmental research and public health, 15(8), 1644.

24. Kulkarni, S., Gilbert, C., Giri, N., Hankare, P., Dole, K., & Deshpande, M. 2022. Visual impairment and blindness among children from schools for the blind in Maharashtra

state, India: Changing trends over the last decade. Indian journal of ophthalmology, 70(2), 597–603.

25. Mezer, E., Chetrit, A., Kalter-Leibovici, O., Kinori, M., Ben-Zion, I., & Wygnanski-Jaffe, T. 2015. Trends in the incidence and causes of severe visual impairment and blindness in children from Israel. Journal of AAPOS: the official publication of the American Association for Pediatric Ophthalmology and Strabismus, 19(3), 260–5.

26. Muhit, M., Karim, T., Islam, J., Hardianto, D., Muhiddin, H. S., Purwanta, S. A., Suhardjo, S., Widyandana, D., & Khandaker, G. 2018. The epidemiology of childhood blindness and severe visual impairment in Indonesia. The British journal of ophthalmology, 102(11), 1543–1549.

27. Musselwhite, K., Cuff, L., McGregor, L., & King, K. M. 2007. The telephone interview is an effective method of data collection in clinical nursing research: a discussion paper. International journal of nursing studies, 44(6), 1064–1070.

28. Newton, J., & Garner, S. 2002. Disease Registers in England. Oxford: Institute of Health Sciences University of Oxford.

29. Nurse Key. 2021. Retrieved from nursekey.com:https://nursekey.com/12-examination-of-feasibility-intervention-and-research-methods/#c12-bib-0004

30. Pizzarello, L., Abiose, A., Ffytche, T., Duerksen, R., Thulasiraj, R., Taylor, H., Faal, H., Rao, G., Kocur, I., & Resnikoff, S. 2004. VISION 2020: The Right to Sight: a global initiative to eliminate avoidable blindness. Archives of ophthalmology (Chicago, Ill.: 1960), 122(4), 615–620.

31. Pawar, N., Ravindran, M., Fathima, A., Ramakrishnan, K., Sithiq, M., & Paranjape, M. 2023. Identification of potential barriers for timely access to pediatric sibling eye check-up in a tertiary eye care hospital. Indian journal of ophthalmology, 71(1), 215–221.

32. Pringsheim, T., Marrie, R. A., Donner, E., Shevell, M., Lam, D., Day, L., Johnston, M.,

Jette, N., & Korngut, L. 2013. Neurological registry feasibility and sustainability. The Canadian journal of neurological sciences. 40(4 Suppl 2), S55–S59.

33. Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. 2004. Meeting the needs of parents around the time of diagnosis of disability among their children: evaluation of a novel program for information, support, and liaison by key workers. Pediatrics, 114(4), e477–e482.

34. Santos-Bueso, E., Dorronzoro-Ramírez, E., Gegúndez-Fernández, J. A., Vinuesa-Silva, J. M., Vinuesa-Silva, I., & García-Sánchez, J. 2015. Causes of childhood blindness in a developing country and an underdeveloped country. Journal francais d'ophtalmologie, 38(5), 427– 430.

35. Ssegawa, J.K., & Muzinda, M. 2020. Feasibility Assessment Framework (FAF): A Systematic and Objective Approach for Assessing the Viability of a Project.

36. Sheasby, L. 2024. What is a patient administration system*?* Retrieved from https://www.theaccessgroup.com/en-gb/health-social-care/software/patient-administration-system/what-is-a-patient-administration-system/

37. Solebo, A. L., Teoh, L., & Rahi, J. 2017. Epidemiology of blindness in children. Archives of disease in childhood, 102(9), 853–857.

38. Solebo, A. L., & Rahi, J. 2014. Epidemiology, aetiology and management of visual impairment in children. Archives of disease in childhood, 99(4), 375–379.

39. Solomon, D. J., Henry, R. C., Hogan, J. G., Van Amburg, G. H., & Taylor, J. 1991. Evaluation and implementation of public health registries. Public health reports, 106(2), 142–150.

40. South African Government News Agency. 2023. Retrieved from sanews.gov.za: https://www.sanews.gov.za/south-africa/921-sa-population-owns-cellphone

41. Unicef, 2022. Retrieved from data.unicef.org: https://data.unicef.org/topic/child-disability/overview/

42. Universal eye health: a global action plan 2014–2019. 2013. Retrieved from World Health Organization: https://www.who.int/publications/i/item/universal-eye-health-a-global- action-plan-2014-2019

43. Wadhwani, M., Vashist, P., Singh, S. S., Gupta, V., Gupta, N., & Saxena, R. 2020. Prevalence and causes of childhood blindness in India: A systematic review. Indian journal of ophthalmology, 68(2), 311–315.

44. Western Cape Government. 2016. New Patient Administrative (AR) and Billing system at Prince Albert Hospital. Retrieved from https://www.westerncape.gov.za/news/new-patient-administrative-ar-and-billing-system-prince-albert-hospital

45. World Health Organisation. 2021. Blindness and vision impairment. Retrieved from https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment

46. https://www.vocabulary.com/dictionary/feasibility

47. World Health Organization. Blindness and Deafness Unit & International Agency for the Prevention of Blindness. 2000. Preventing blindness in children: report of a WHO/IAPB scientific meeting, Hyderabad, India, 13-17 April 1999. World Health Organization.

ABSTRACT

Investigating the factors that determine successful follow up of children diagnosed with incurable blindness using health information collected during their visits to the Red Cross Children's Hospital.

Background

Most children diagnosed with incurable blindness will need access to health, education, and social services, to support them during their potentially high number of disabled life years. The accuracy of key informants' contact information is therefore essential to ensure that proper follow up is carried out, so that the necessary services are available to them. We investigated the factors determining successful follow up of children diagnosed with incurable blindness during their visits to the Red Cross War Memorial Children's Hospital (RXH) in Cape Town, using their health information.

Methods

This was a quantitative cross-sectional study, using data from a cohort of blind children who were referred to a blind school from 2011 to 2020, a total of 178 children, from 0 years up to 12 years of age. Contact information was collected from the children's hospital files at the Red Cross Children's Hospital. Using the telephone numbers obtained, calls were made, and the results of the calls were recorded. For those calls that were responded to, an introduction of who the researcher is, was made, then the purpose and explanation for the call was provided and the respondent was informed that participation is voluntary and that the interview can be stopped at any time should the respondent wish to do so. After that, consent to proceed with an interview was requested, and after it was granted, the researcher explained to the respondent that a few questions about the child's whereabouts, and basic information about health, education and social activities will be asked.

A second round of calls were made, using an identifiable cell phone number. This was to ensure that for all the parents or guardians with whom contact was made but were not reachable for any reason during the initial round, a second attempt was made to reach them. Lastly, the nurse of the blind school was interviewed to triangulate the results of the telephonic interviews. The interview with the nurse was to confirm, whether the children on the data list were registered with the school as well as to ascertain the support services that

are on offer at the school for the blind.

Results

The findings of the study indicated that of the total of 178 participants' folders checked, 127 (71%) folders did contain real and contactable telephone numbers, 10 (6%) folders had incorrectly recorded contact numbers, and 41 (23%) folders had no contact numbers as they were missing. Of the 127 folders with contactable numbers, only 29 (23%) of the key informants responded. Of these, 25 out of 29 (86%) confirmed that the children were alive with 4 (16%) mortalities reported. With regards to information on various support services offered, 7 out of 25 (24%) confirmed to have access to health services, which included hospital visits on scheduled appointment dates, with 16 (64%) receiving support for social services such as grants for relief on financial burden and 15 (60%) of the children are in receipt of education support services or attending special schools.

Conclusion

As evidenced by the low response rate, contact with most of the parents was not achieved, resulting in less data to inform us of successful follow of the children. This lack of success can be attributed to the high inaccuracy in the capturing of the contact details, in the missing contact numbers as well as calls for some contacts which were no longer in-service.

While little can be done with numbers being out of service, the incorrectly captured information coupled with lack of contact numbers requires that further scrutiny is applied to the patient folders when recording their information and that regular checks and updates are done to ensure that contact numbers are available and that they are accurate.

.

THE FACTORS THAT DETERMINE SUCCESSFUL FOLLOW UP OF CHILDREN DIAGNOSED WITH INCURABLE BLINDNESS USING HEALTH INFORMATION COLLECTED DURING THEIR VISITS TO THE RED CROSS CHILDREN'S HOSPITAL.

Background

There is a high burden of blindness in children that are in developing countries (Alrasheed, 2021; Burnett et al, 2018). Blindness refers to a lack of vision which may happen suddenly or over some time due to many reasons (Markos, Kefyalew & Tesfaye, 2022). while the WHO, (2021) defines blindness as presenting with visual acuity worse than 3/60 in the better eye.
It is estimated that every minute a child goes blind in both eyes in a developing nation (Shrestha,2011). For the majority of affected children, visual disability starts early, caused by disorders arising in the 'first 1001 days' of postconceptional life (Solebo et al, 2023).

Many blind children die in childhood from the underlying causes of their blindness: measles, vitamin A deficiency (VAD), meningitis, rubella, prematurity, genetic disease or head injury (Demissie & Solomon, 2011). Although vision problems in children account for a relatively low percentage (0.4-0.5%) of those with visual impairment (Unicef.org, 2021), the prevalence of blindness in children is estimated to be second only to adult cataracts in terms of "blind person-years (Gilbert & Foster, 2001; Gudlavalleti, 2017). Sub-Saharan Africa has an estimated three hundred thousand blind children, while in the Asian region, the number of blind children is approximately one million (Solebo, Teoh & Rahi, 2017).

The high prevalence of childhood blindness and visual impairment has been attributed to poor access to primary health care facilities or inadequately trained medical personnel (Gilbert, 2007; Hussain et al., 2019). Further disadvantages for blind children are the limited number of services available in LMIC setting and the lack of availability of paediatric ophthalmologists. There are only 26 paediatric eye-care centres in sub-Saharan African countries serving 787 million with a ratio of one paediatric eye care centre for 30.3 million children (Alrasheed, 2021).
In a study conducted by the International Council of Ophthalmology (ICO), it was stated that, of a total number of ophthalmologists available worldwide, two thirds of them come from developed countries while only a third of them come from lower- and middle- income countries (LMICs) (Adio & Komolafe, 2013). This limited number of available trained medical

staff adds to the burden already experienced in LMICs settings as only a selected few would be able to access services that are beneficial to them, thereby further pushing them below poverty levels, in turn reducing their chances of an improved quality of life. On the other hand, these services may be available but making use of them is not possible due to certain challenges. Alrasheed (2021) states that, in some countries where paediatric eye services exist, they are underutilized because of barriers such as socio-economic status, cultural beliefs, and unawareness of signs and symptoms (Alrasheed, Mohamed & Alluwimi, 2024).

In a study looking at health seeking behaviour, it was reported that, some parents mentioned that, they did not seek eye care because of their "fear of the treatment options that might be required", while for other parents it was due to logistical reasons as some of the parents complained of not having time to take their children for a proper check-up (Ebeigbe, 2018).

Childhood blindness and visual impairment is a major cause of psychosocio-economic problems in children and their families (Solebo & Rahi, 2014; López Ulloa, Burn & Beauregard, 2021; Eze et al,2024). In most cases, these negative effects usually continue into adulthood, affecting their quality of life through their inability to be economically active, productive, and socially interactive (Mezer et al., 2015; Heijthuijsen et al., 2013). In poor communities, the families of children with visual impairment carry additional burdens of high cost for health and educational services (Mannava, Borah & Shamanna, 2024).

In a study looking at early parent child relationship, Gui et al.,(2023) posits that, families of totally blind children might feel particularly isolated because of this stigma. They are at risk of withdrawing from their social circles due to a combination of physical and mental overburden linked to medical care, concerns about the future and their children's development, and experience of exclusion.

Reducing vision loss in children has the benefit of restoring to a child a quality of life of up to ten times that of restoring the sight of an adult with blinding cataract (Gilbert & Foster, 2001). However, the processes of identifying, referral, diagnosis and treatment / rehabilitation of children with visual impairment are hampered by many challenges, including lack of resources, appropriate skills, equipment and supplies (Gilbert & Foster, 2001; Hussain et al., 2019; Alrasheed, Mohamed & Alluwimi, .2024). Structural, ethical and policy issues further hamper the planning and implementation of effective intervention strategies (Solebo & Rahi, 2014).

Purpose

This study was aimed at investigating the factors that determine successful follow up of children diagnosed with incurable blindness by ascertaining the accuracy and usefulness of contact information collected during their visits to the Red Cross War Memorial Children's Hospital (RXH), this information collected from 1 January 2011 to 31 December 2020.

The objectives of the study were:

a) To determine the accuracy of the contact information of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
b) To identify the reasons for inaccurate contact information of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
c) To determine the loss to follow-up rate due to inaccurate contact information of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
d) To determine the rate of uptake of health services of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
e) To determine the rate of uptake of education services of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.
f) To determine the rate of uptake of social development services of children diagnosed with incurable blindness at RXH from 1 January 2011 to 31 December 2020.

Obtaining this information will help to identify strategies that will ensure that contact information from key informants is up-to- date and useful for follow-up. This in turn will contribute towards the provision of information for interdisciplinary management of children affected by blindness and severe visual impairment.

Methodology

A quantitative, cross-sectional study methodology was used for this study, using records from children who had visited Red Cross Children's Hospital (RXH) as the study population. The study sample was made up of hospital records of children who had been diagnosed with incurable blindness and referred to Athlone School for the Blind from January 2011 until

December 2020. Prior to collecting data, an *MS Excel* spreadsheet of these children's names and folder numbers was used for cross referencing with their contact numbers on the patient record kept in the hospital's health information system.

After obtaining ethical approvals from the Human Research Ethics Committee (hrec) at UCT and the Western Cape Department of Health, patient record cards were accessed from the hospital, to collect contact details of the primary caregivers (key informants) of the children.

After collecting the primary caregivers' telephone numbers, the caregivers were called from the RXH Eye Department phone (number showing) with the aim to conduct a brief interview.

The telephonic interviews were based on a questionnaire with a set of structured questions consisting of three sections focusing on: primary key informant details including biographical details, follow-up details such as follow-up dates at the hospital, education and school attended, information on services received such as social support, health support, or other services, as well as primary caregiver details including information on support grants and care givers 'occupation.

A second round of interviews was conducted from a personal cell phone, showing the number of the cell phone.

As a follow up, a meeting with the nurse responsible for the children at the Athlone School for the Blind was held to verify the information obtained from the referral list, and the data collected during the interviews.

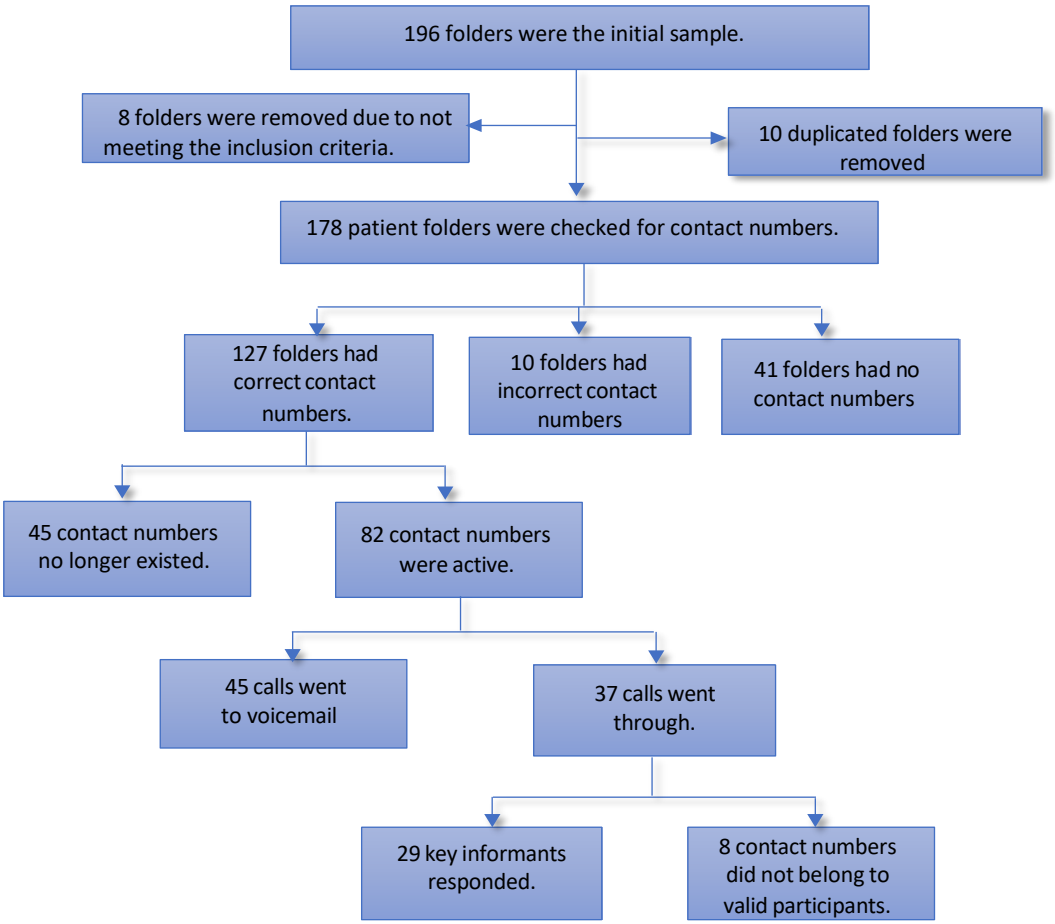
The data collected was captured on an MS Excel spreadsheet, and after cleaning, simple descriptive analysis was using the *R Studio* statistical software (version 4.3.1)

For data analysis, a data sheet was created containing various variables such as: gender, call status, consented calls, alive, school attendance as well as social and health support.

Results

There were 178 available folders of children diagnosed with incurable blindness and visual impairments at the Red Cross War Memorial Children's Hospital (RXH), from 1 January 2011 to 31 December 2020. (*diagram 1*)

Diagram 1 : Number of children on the referral list



After thoroughly checking all the presented folders, It was established that, a total of 127 (71%) had correct and contactable numbers for potential phone calls to be made.

10 (6%) of these folders could not be considered as they contained incorrectly recorded contact numbers, which were either a digit too short or too many which did not correspond to the 10-digit number system in use in South Africa.

A further 41 (23%) of these were missing any care givers' contact details altogether, either due to an administrative oversight or may not have been provided by the caregiver for various reasons unknown. This meant that only a total of 127 folders could be considered for phone calls due to correctness of recorded digits. (*diagram 1*)

Distribution by gender

When the total of the children was broken down by gender, the sample was comprised of 91(51%) males and 87 (49%) females, showing more or less an even spread of genders that were attended to at the hospital.

The children's ages based on their dates of birth also ranged from zero at birth to 12 years of age at the time of referral.

When looking at the overall number of children and categorizing the ages by various stages, such as early childhood development (ECD), (0-4 years), foundation phase (5-9 years) , intermediate phase (10 -12 years). Statistically the children who were between the ages of birth to 4 years for both genders showed a higher proportion than the other age groups with a total of 122 (69%). When these were stratified even further, according to gender, there were 66 (73%) out of 91 males, whereas for the girls it was 56 (63%) showing an even distribution of gender in that age group. (*table 1*)

Table 1: Distribution of the children's age by gender at referral

AGE	***MALE(n=91)***	***FEMALE (n = 87)***	
		Male(%)	***Female (%)***
0 – 4years	66	37%	56	31%
5 – 9 years	17	10%	25	14%
10 years	7	4%	5	3%
Unknown	1	0.5%	1	0.5%
Total	91	51.5%	87	48.5%

Call activity

For the phone call activities, the 127 potential contact numbers were recorded to be called. Upon attempting to establish contact with the numbers, only 82 (65%) of the contact numbers were active, which was proven by the ringing upon dialing. A total of 45 (35%) of these dialed numbers did not exist on their respective service network providers, an indication that they have been disconnected which could also have been due to various reasons such as lost sim cards, changed numbers, relocations and others.

Of the active contact numbers, 45 (55%) out of 82 were dialed but they did not ring nor go

through but went directly to voicemail. This then left only a handful of 37 (45%) numbers with which calls were made and answered. (*Table 2*)

Table 2: Status of the folders with contact information

FOLDER STATUS	CALL STATUS	TOTAL	
		Number	Percentage (%)
Folders with contactable numbers	Responses	29	16%
	Voicemail	45	25%
	Someone else's number	8	5%
	Number does not exist	45	25%
		127	**71%**
Folders with no contactable numbers	Incorrectly recorded contact numbers	10	6%
	No contact numbers	41	23%
		51	**29%**
		178	**100%**

Response rate

There was a total of 37 participants who responded after being called, it was established that, 8 (22%) of these participants were not the expected key informants as those contact numbers belonged to the wrong person, according to the respondents, and therefore had to be ruled out, leaving a total of 29 (78%) contacts that belonged to key informants.

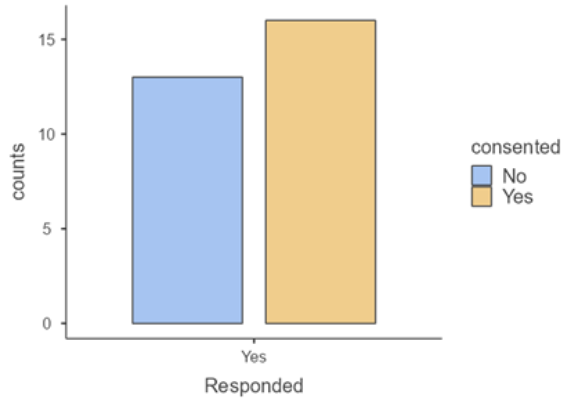
Respondents

Of the 29 respondents who answered their phones, 16 (55%) consented to the call and granted an interview. Interviews with 13 (45%) of the respondents could not take place, this was due to consent not being granted by some of the care givers, while some opted to not continuing with the interview and another reason was due to the child reported to have passed away. (*Graph 1*)

Overall, this resulted in a total of 16 out of 25 (64%) respondents providing and confirming

information on the various support services provided as well as verification of any school attendance by the blind child.

Graph 1: Status of respondents



SUPPORT SERVICES

As part of the interview, the parents were asked questions on whether they were able to access health support services, and what type of services they were able to access. Some of their responses ranged from being able to get walking sticks where needed while some were taught to read in Braille as a way to equip them with a skill. For others there was access to physiotherapy through the school for the blind for any other conditions they also have.

Social support services include being registered to receive a type of a grant, whether it is a social care grant, child support grant or disability grant to assist towards the needs of the blind or visually impaired child while in the care of the parent. This social support service is offered through the department of social services through the recommendation and referral of the ophthalmologist based on the circumstances of the child.

Education support services are received through referral by the treating ophthalmologist to a special school, in this case the ASfTB being the referral school. For our context, the data used was of information of children who were referred to the school for the blind.

The ASfTB is situated in Bellville and admits children who are blind and those who have a range of visual impairments. Admission of these children starts from the early childhood development (ECD) stage, which is the preschool age of between 4-6 years old, up until the matric year of schooling. It accommodates day scholars, some of whom are transported to and from the school as well as having a hostel to accommodate others. The use of the school bus

or even staying at the hostel can also be considered as social support as the daily travelling for some of the children can be challenging due to staying quite far and their special need.

Health support services

The information that was used for statistical purposes was of the parents, who not only responded to the calls but those who consented to the interviews as that was also a means to verify information. With regards to health support, 7 (44%) out of 16 children were reported by their parents as receiving health support services, while 9 (56%) reported that no health support was received in any form.

Social support services

During the interview, the parents were asked if they were in receipt of any form of social support, this was specifically asking about the receipt of any grant for the child. As there were several grant types available, all of the parents (100%) were able to confirm that they do receive a grant, depending on the type of grant for which they qualified. This was very positive as it means that some form of financial assistance is provided for the children.

Education status

The interview conducted at the Athlone School for The Blind (ASfTB) was aimed at verifying the school status of the blind and visually impaired children that are on their register as it was the referral school selected by the hospital. The verification was to ensure that the information matches with that on the spreadsheet.

It was established that 55 (31%) of the children were registered at the school as confirmed by the nurse. The list also included some of the children who had already left the school due to reaching school leaving age or completion of matric. Most of the children on the list 123 (69%) could not be confirmed as they did not appear on the school's register including 4 (2%) were deceased.

The total number of children that were attending school regardless of the type registered at, was 60 (34%) out of 178. One child (1%) had applied and waiting for acceptance at ASfTB. One of the interviewed caregivers confirmed that their child was not accepted at the school as the child needs specialized care and is on nappies, something not within the capacity of

the blind school.

A stratification based on the consented calls provides the following information, 9 (56%) out of 16 caregivers confirmed that their child is registered at ASfTB. 5 (31%) confirmed that their children do attend special schools in and around their areas. While with the other 2(13%), one was on the waiting list for school at ASfTB and the other was not at any school. (*table 3*)

Table 3: Characteristics of the respondents

VARIABLE		NUMBER	PERCENTAGE (%)
School attending			
	Athlone School for the Blind	9	56%
	LOFOB preschool	1	6.3%
	Erica Frail Care, Rocklands	1	6.3%
	Project Playground, Langa	1	6.3%
	Sibongile day care centre, iLitha Park	1	6.3%
	Zamokuhle Special School, Bizana EC	1	6.3%
	Applied at ASfTB	1	6.3%
	Not attending a school	1	6.3%
Health support			
	Yes	7	44%
	No	9	56%
Social support			
	Yes	16	100%
	No	0	
Grant type received			
	Child support	5	31%
	Care dependency	3	19%
	Disability	7	44%
	Child support & disability	1	6%

Discussion

The study started off with a total of 178 folders that were meant to be contacted to get telephone numbers, as a means to determine the extent of loss to follow up of blind children as it was anticipated that this was on a high scale, especially for the blind children. The collection of this information would then play a significant role in informing stakeholders,

policy makers and other entities of the steps necessary to plan and implement the Childhood Blindness Register, all this once an analysis of the information has been done, with the ultimate goal of pooling together all the available information on children with irreversible blindness centrally.

It was, however, established that, of all the available folders checked, only a handful of telephone numbers were contactable; specifically of those who responded, only 29 (16%) can be considered a success. 98 (55%) contact numbers comprising of those that are out of service, those that went directly to voicemail and those that belonged to a different person skew the research considerably as it is not adequate. The rest of the 51(29%) folders consisting of incorrectly recorded numbers and those that had no numbers at all also pose a challenge for the research and further reduces its reliability. This reduction in data means that there is no clear conclusion to be drawn on the success of the follow up and might have an impact on the planning and goals of the CBR due to insufficient information.

Some possible reasons for the poor outcome of the calls are that, as the initial sample included patient-folders from January of 2011 to December of 2020 , it could be that these contact details are no longer registered on any networks and maybe be blocked by the service providers or might have relocated to other countries. The parents may also be in possession of new numbers that they have yet to update or the caregiver may also not be aware of means to do a sim card swop or have opted not to do any at all.

The calls going to voicemail can be taken as an indication that the contact numbers are still active but that, the timing of the call was an issue or there might have been poor network connectivity at the time the researcher made the call.

It is also important to note that, the researcher was only able to make calls during the day and on weekdays which is typically during working hours for some people. Another fact is that calls were coming through to potential respondents from an unfamiliar number and may have chosen to ignore the call altogether.

Although there was no available research found that has done studies on reasons why people do not answer unknown numbers, there is some anecdotal evidence as to why that is the case. For instance, people who own cell phones can also be bombarded with a lot of calls, sometimes at awkward times making it impossible for one to answer a call.

In an online article by Peoplocity.com, asking why people do not answer unknown numbers, one of the reasons that came up was that. “A phone call interrupts what you are doing, and whether you’re at work or at home, it’s distracting. A call can also be time consuming”(Peoplocity.com,2018).

Another challenge with cell phones is that you maybe at a place that makes it challenging to answer a call due to the lack of privacy especially if it rings at a place where there are lot of people which makes it difficult to say certain things.

Due to the increased number of cell phone usage, it is not uncommon for people to change their contact numbers frequently and those numbers being recycled, resulting in calls that are sometimes not familiar to the receiver and them not answering those unknown numbers. An important factor also to be considered, that makes people reluctant to answer unknown contact numbers is the fear of being scammed resulting in the theft of their personal information.

The missing contacts or inaccurate recording, speak to proper administration that needs to be looked at for quality control purposes.

There were poor results determined on social and health support services, this was due to the low response rate, which leaves the information of the uptake of these services undetermined with only less than 10% of these services being received out of 178.

The school for the blind did confirm that it offers some health support by assisting with the collection of the children’s medications, for those who require it. It also provides Braille tuition for the children who require these lessons for their learning, which is also taught at the school. This support however cannot be quantified by the researcher as it was just mentioned in brief of its availability.

Again, it is hard to conclude as to whether a large number of the children are registered for schooling as there were many that could not be verified and therefore remain unknown with only 55 (31%) who could be actually verified.

Limitations

The interviews with the caregivers were initially conducted at the hospital using a landline. Due to challenges with the handset used to make the calls, on the days data collection was to take place, an alternative needed to be made. Some added challenges were related to the

time the calls were being made due to researcher availability. The location and handset were changed to ensure that data collection continued as planned, however the use of a cellphone may be considered as a limitation as it may have been the reason for the low response on some of the calls made due to it being an unfamiliar number. The use of a telephone as an interview method in itself is a limitation as it may not be reliable for data collection due to unpredictability.

With regards to the spreadsheet containing the children's names and information, a limitation thereof was that it was the only form available to work with, additionally there were a number of the patients' details that were spelled incorrectly with some of the columns missing some information. This made verification of the details at the school challenging as other forms of verification needed to be employed such as folder numbers making the process take longer or not possible due to missing information.

The folders that were used were based on referrals to the blind school only and this limits the reach to caregivers to only those who have children at the school. As indicated by those not registered at the school, it means that those who could not be verified could also be at other schools. This does leads to exclusion of potential data therefore resulting in information bias.

Sample size was not considered in the methodology as the cases were already in existence, but future studies could determine whether there were any differences between "older" and "newer" cases from 2011 to 2020.

Conclusion

It is evident by the available statistics that there was limited success in reaching the set out objective of contacting the respondents. This inability to contact a larger pool of potential respondents has an impact in the overall outlook of the study and its validity as it is not fully representative of the sample, thereby leading to response bias.

The hospital management and the school management need to work in collaboration to make sure that there is sharing of information to support efforts to better care for the blind child.

As the data collection relied on the accurate and up to date contacts from the patient folders for its success, it is therefore crucial that, the administration dealing with contact information is revisited and rectified to ensure that all information of the patients' folders is valid. In the

case where the contact numbers were incorrect, validation could be carried out by having a space containing 10 blocks, that way it will make it easier to detect if the digits are too little or to many and this can be followed by calling out the numbers for confirmation. Another method of validation could be to send a one-time password OTP) to the parent's contact number so that they may verify and authenticate their number while in the presence of an administrator. As people sometimes change telephone numbers, regular updates and routine confirmation need to be conducted to ensure that correct and up-to-date information is available. A much more cost effective and quick method is to call out the numbers as the person is calling them as this makes the validation instant.

To conclude, to rely only on telephone numbers to make contact has been proven to be inadequate as mistakes tend to happen when recording these. Therefore, very rigorous measures need to be employed to make sure that these are accurate and up to date.

References

1. Adio A.O., Komolafe, R.D. 2013.The State of Paediatric Eye Care in Nigeria: A Situational Review and Call for Action. Nigerian Health Journal,13(1):1-6.

2. Alrasheed, S. H., Mohamed, Z. D., & Alluwimi, M. S. 2024. Childhood visual impairment causes and barriers to accessing eye care: A suggested approach for Africa. African journal of primary health care & family medicine, 16(1), e1–e7.

3. Alrasheed, S. H. 2021. A systemic review of barriers to accessing paediatric eye care services in African countries. African health sciences, 21(4), 1887–1897.

4. Burnett, A. M., Yashadhana, A., Lee, L., Serova, N., Brain, D., & Naidoo, K. 2018. Interventions to improve school-based eye-care services in low- and middle-income countries: a systematic review. Bulletin of the World Health Organization, 96(10), 682–694.

5. Demissie, B. S., & Solomon, A. W. 2011. Magnitude and causes of childhood blindness and severe visual impairment in Sekoru District, Southwest Ethiopia: a survey using the key informant method. Transactions of the Royal Society of Tropical Medicine and Hygiene, 105(9), 507–511.

6. Ebeigbe J. A. 2018. Factors influencing eye-care seeking behaviour of parents for their children in Nigeria. Clinical & experimental optometry, 101(4), 560–564.

7. Eze, U. A., Obasuyi, O. C., Salihu, D. V., Bature, M., Yeye-Agba, O. O., & Kanmodi, K. K. 2024. Prevalence and Causes of Blindness and Visual Impairment Among Nigerian Children: A Systematic Review. Clinical ophthalmology (Auckland, N.Z.), 18, 289–301.

8. Gilbert, C. 2007. Changing challenges in the control of blindness in children. Eye (London, England), 21(10), 1338–1343.

9. Gilbert, C., & Foster, A. 2001. Blindness in children: control priorities and research opportunities. The British journal of ophthalmology, 85(9), 1025–1027.

10. Gilbert, C., & Foster, A. 2001. Childhood blindness in the context of VISION 2020--the right to sight. Bulletin of the World Health Organization, 79(3), 227–232.

11. Gudlavalleti, V. S. M. 2017. Magnitude and Temporal Trends in Avoidable Blindness in Children (ABC) in India. Indian journal of pediatrics, 84(12), 924–929.

12. Gui, A., Perelli, D., Rizzo, G., Ferruzza, E., & Mercuriali, E. 2023. Children's total blindness as a risk factor for early parent-child relationships: preliminary findings from an Italian sample. Frontiers in psychology, 14.

13. Heijthuijsen, A. A., Beunders, V. A., Jiawan, D., de Mesquita-Voigt, A. M., Pawiroredjo, J., Mourits, M., Tanck, M., Verhoeff, J., & Saeed, P. 2011. Causes of severe visual impairment and blindness in children in the Republic of Suriname. The British journal of ophthalmology, 97(7), 812–815.

14. Hussain, A., Ferdoush, J., Mashreky, S. R., Rahman, A., Ferdausi, N., & Dalal, K. 2019. Epidemiology of childhood blindness: A community-based study in Bangladesh. PloS one, 14(6), e0211991.

15. Kemmanu, V., Hegde, K., Giliyar, S. K., Shetty, B. K., Kumaramanickavel, G., & McCarty, C.A.2016. Prevalence of Childhood Blindness and Ocular Morbidity in a Rural Pediatric Population in Southern India: The Pavagada Pediatric Eye Disease Study-1. Ophthalmic epidemiology, 23(3), 185–192.

16. Khandekar, R., Kishore, H., Mansu, R. M., & Awan, H. 2014. The status of childhood blindness and functional low vision in the Eastern Mediterranean region in 2012. Middle East African journal of ophthalmology, 21(4), 336–343.

17. López Ulloa, J. A., Burn, H., & Beauregard, A. M. (2021). Causes of Blindness and Visual Impairment in Early Childhood at a Low Vision Service in Mexico City: A 15-year Review. *Ophthalmic epidemiology*, *28*(5), 420–427.

18. Mannava, S., Borah, R. R., & Shamanna, B. R. 2024. Measuring utility values of eye conditions among children in India using the EQ-5D-Y instrument. Health economics review, 14(1), 72.

19. Markos, M., Kefyalew, B., & Tesfaye, H. B. 2022. Pooled prevalence of blindness in Ethiopia: a systematic review and meta-analysis. BMJ open ophthalmology, 7(1), e000949.

20. Mezer, E., Chetrit, A., Kalter-Leibovici, O., Kinori, M., Ben-Zion, I., & Wygnanski-Jaffe, T. 2015. Trends in the incidence and causes of severe visual impairment and blindness in children from Israel. Journal of AAPOS: the official publication of the American Association for Pediatric Ophthalmology and Strabismus, 19(3), 260–5.

21. https://peoplocity.com/2018/08/09/phone/

22. Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. 2004. Meeting the needs of parents around the time of diagnosis of disability among their children: evaluation of a novel program for information, support, and liaison by key workers. Pediatrics, 114(4), e477–e482.

23. Shrestha U. D. 2011. Tertiary eye care centre model for development of paediatric cataract surgery services in developing countries. JNMA; journal of the Nepal Medical Association, 51(183), 154–156.

24. Solebo, A. L., Teoh, L., Sargent, J., Rahi, J. S., & British Childhood Visual Impairment and Blindness Study Interest Group 2023. Avoidable childhood blindness in a high-income country: findings from the British Childhood Visual Impairment and Blindness Study 2. The British journal of ophthalmology, 107(12), 1787–1792.

25. Solebo, A. L., Teoh, L., & Rahi, J. 2017. Epidemiology of blindness in children. Archives of disease in childhood, 102(9), 853–857.

26. Solebo, A. L., & Rahi, J. 2014. Epidemiology, aetiology and management of visual impairment in children. Archives of disease in childhood, 99(4), 375–379.

27. Unicef ,2021. Retrieved from data.unicef.org: https://data.unicef.org/topic/child-disability/overview/

28. World Health Organization. 2021 .Fact sheets detail in blindness and visual impairment: https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment