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Do neonatal intensive care unit (NICU) health workers know about retinopathy of prematurity (ROP)? A qualitative study at a Regional Referral Hospital in Uganda

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ABSTRACT

Introduction Retinopathy of prematurity (ROP) is a significant cause of blindness and visual impairment in preterm infants globally, particularly in low-income and middle-income countries. ROP is associated with prematurity, and with the increase in the survival of preterm infants, its global burden continues to rise. However, there is limited information available on health workers' perspectives regarding ROP in Uganda.

Methods This qualitative study explored health workers' experiences regarding ROP in the neonatal intensive care unit (NICU) at Hoima Regional Referral Hospital. This study involved in-depth interviews with eight health workers working in the NICU. We examined individual, facility and national factors that could impact the health workers' perspectives on ROP at the hospital. The data obtained were transcribed and coded, and themes were generated for further analysis.

Results We identified key barriers and facilitators to effective ROP care. Four major themes emerged from the analysis: (1) Knowledge and awareness of ROP, (2) Challenges and limitations in implementing the ROP screening programme, (3) Training and guidelines for ROP screening and treatment and (4) Recommendations for ROP prevention screening and management. ROP awareness, knowledge of ROP and witchcraft and ROP were identified as specific subthemes under the knowledge and awareness of ROP theme.

Discussion and conclusion This study reveals significant gaps in health workers' knowledge and awareness of ROP. Limited access to essential equipment and specialised personnel may further limit ROP screening capacity. We suggest implementing a multidisciplinary team approach, continuous professional development and establishing national ROP guidelines. We recommend developing a formal training structure and syllabus for ROP screening. The training can enhance task shifting among health workers in areas without specialised health workers. Addressing the identified barriers is crucial for improving the care and outcomes for preterm infants in Uganda and similar settings.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ There is limited information about the knowledge and perspectives of retinopathy of prematurity (ROP) among health workers in low-income and middle-income countries, which affects effective ROP management.

WHAT THIS STUDY ADDS

⇒ Health workers lack sufficient knowledge to manage preterm infants with ROP.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study provides a basis for further exploring ROP knowledge among health workers in other settings and the need for ROP-tailored training.

INTRODUCTION

Retinopathy of prematurity (ROP) is a vaso-proliferative disorder affecting preterm infants of lower gestational age and birth weight. ROP is a significant global public health concern with the increased prevalence of preterm births.[1] Annually, 20 000 infants are declared blind and over 30 000 suffer from significant visual impairments as a result of ROP.[2] Further, a recent meta-analysis demonstrated a 31.9% pooled global prevalence of ROP among preterm infants from 1985 to 2021, with a higher prevalence noted in lower-income and middle-income countries.[3] Across Africa, data on ROP burden have been reported from eg,ypt, Nigeria, Kenya, South Africa, Sudan and Rwanda with a 30% pooled

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prevalence.[4 5] The only study exploring the burden of ROP in Uganda was a 2023 multicentre study, which found a pooled prevalence of 6% among 331 preterm infants in two Ugandan referral hospitals.[6]

Despite advances in neonatal care, ROP remains a significant public health concern, particularly in low-income and middle-income settings including Uganda.[7 8] Effective ROP management requires timely diagnosis and specialised interventions.[9] These requirements are constrained by limited resources, insufficient training in ROP screening and management pathways and a lack of ROP awareness, including knowledge regarding its' screening, diagnosis and management, among health workers.[10] This leads to ineffective service delivery to preterm infants.[6] Therefore, the perspectives of health workers about ROP in the healthcare settings handling preterm infants are crucial.

However, there is limited research exploring the perspectives of health workers about ROP in Uganda. This study examined the perspectives and experiences of health workers regarding ROP at a regional referral hospital in Uganda. We also examined the barriers, facilitators and potential solutions to improve ROP care. Given the complexity of the factors that influence health workers' practices, the social-ecological model (SEM) was employed in this study. The SEM asserts that behaviour is affected by multiple levels of influence, including at the individual, interpersonal, organisational, community and policy level.[11 12] The interaction of these layers helped us evaluate health workers' perspectives on ROP care. By understanding health workers' perspectives, we sought to inform strategies to strengthen ROP services, especially at the regional referral level, and enhance strategies to improve health workers' awareness of ROP. We also sought to improve the overall visual outcomes for vulnerable preterm infants in Uganda.

METHODS

The study was conducted at the neonatal intensive care unit (NICU) at Hoima Regional Referral Hospital (HRRH). HRRH is located in Bunyoro Region in Mid-Western Uganda Hoima City, 200 km West of Kampala, the capital city of Uganda.[13] The hospital serves approximately 3 million individuals from the Bunyoro region, covering districts such as Hoima, Kibale, Masindi, Buliisa, Kiryandongo, Kyankwanzi and Kiboga.[13] About 180–190 infants are received at the HRRH NICU every month, with an average of 80 born preterm and around 10 referrals from lower health facilities. Most of the preterm infants admitted are of 28–32 weeks gestational age and in the very low birth weight category between 1000 and 1500 g. Admissions for extremely low birth weight of less than 1000 g occur occasionally. Respiratory support at the facility includes improvised fixed-pressure continuous positive airway pressure oxygen delivery and oxygen monitoring using portable pulse oximeters. Oxygen blending, saturation monitoring and intubation are not available. By June 2024, the NICU had 14 health workers: 1 neonatology fellow, 1 paediatrician, 4 midwives, 3 registered nurses, 2 intern nurses and 3 intern doctors.

We conducted a descriptive qualitative study involving in-depth interviews among eight health workers from June to July 2024. Study participants were recruited into the study where convenient according to their availability and proximity during the data collection. Inclusion criteria were set for health workers who had spent at least a month in the NICU and were directly involved in preterm care. Ophthalmic clinical officers (OCOs) who had screened the preterm infants for other eye conditions excluding ROP were included in the study. Written consent was sought and obtained from these health workers by two research assistants (RAs) who were initially trained in qualitative data collection. Confidentiality was achieved by eliminating the participants' names and National Identification Numbers. Administrative approval was obtained from the hospital administration to access the facility's health workers in the NICU department. The consented participants were interviewed for 30–80 min until saturation.

One RA took notes while the other asked the guiding questions and recorded them. The transcriptions were checked for inconsistencies by IA and EM. AT and NA proofread the final transcript versions. The specific six steps that followed in the thematic analysis conducted by PA were: (1) familiarising oneself with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and (6) producing the report. After reading two randomly chosen transcripts, PA developed a codebook using ATLAS.ti software to guide the analysis for the remaining interviews through relational content analysis. During the data analysis process, PA, IA, EM and NA held regular meetings to harmonise identified themes and discuss data interpretations. We (PA, IA, EM and NA) selected quotes to reflect each category and illustrate the different themes. Adherence to the Consolidated Criteria for Reporting Qualitative Research checklist was prioritised to ensure rigorous research reporting, and a report has been annexed.[14] The SEM informed data collection to explore the different perspectives of health workers on ROP. The theory provides a key framework for examining the contextual factors that influence these perspectives, as illustrated in figure 1.[15]

Patient and public involvement

No patient was involved in this study.

RESULTS

Eight health workers working in the NICU at HRRH, with a mean age of 34.6 years, a range of 26–50 years, and a 1:1 male-to-female ratio, were interviewed. Two were OCOs attached to the entire hospital, and three were intern doctors with one intern nurse, one nursing officer with neonatal training and one registered nurse. Four major

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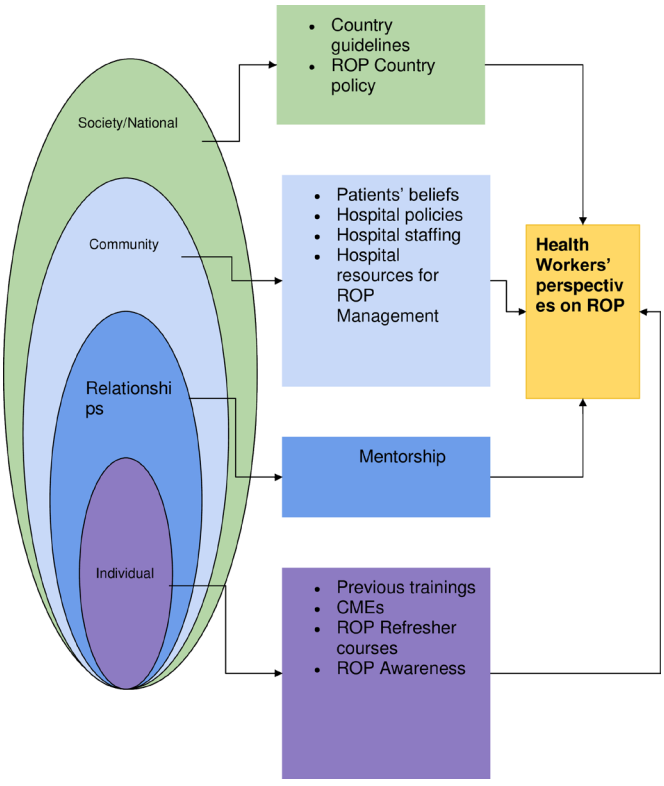


Figure 1 An illustration of the multilevel factors influencing the health worker's perspectives about ROP based on the SEM personal characteristics. CMEs, continuous medical education; ROP, retinopathy of prematurity; SEM, social-ecological model.

themes emerged from the analysis: Knowledge and awareness of ROP, challenges and limitations in implementing the ROP screening programme, training and guidelines for ROP screening and treatment, and recommendations for ROP prevention screening and management, as shown in table 1.

THEME I: KNOWLEDGE AND AWARENESS

The knowledge and awareness theme consists of three subthemes: ROP awareness, knowledge of ROP and witchcraft and ROP.

Subtheme i: ROP awareness

Health workers became aware of ROP while practising in the NICU. Most of them noted that ROP was a condition that was not prioritised during healthcare service. The majority (6 out of 8) lacked sufficient knowledge about ROP. They mentioned that awareness about ROP was minimal due to limited sensitisation in the facility and region. Two quotes from the health workers are noted below.

> "…I think most of them don't know about it. You find that even us, it had skipped our minds until someone came to talk about it…" Health worker 1

> …because even the health workers also don't know. Their source of information was empty, I could say…… Health worker 2

Subtheme ii: knowledge of ROP

Health workers reported varying knowledge about ROP and its associated dynamics, such as screening, diagnosis, treatment and follow-up. The health workers vaguely knew that ROP happens among preterm infants, especially those who have been on unblended oxygen therapy for a long time.

> …Well, generally, what I know is that, of course, it happens in preterm infants; it happens in preterm infants who have been on oxygen therapy for a long time…. Health worker 1

> …Though during the training, they told us that people born and put on oxygen get that condition of ROP… Health worker 4

> ……even the health workers, unless someone has gone into that department of eyes, they also do not know. I imagine someone down there will be hearing it for the first time; people think that blindness happens in old age…. Health worker 5

Table 1 A table showing the different thematic areas obtained from the analysis

Major theme	Subtheme
Knowledge and awareness of ROP	ROP awareness
	Knowledge of ROP
	Witchcraft and ROP
Challenges and limitations in the implementation of the ROP screening programme	ROP screening equipment
	Human resources for ROP screening
Training and guidelines for ROP screening and treatment	ROP training
	ROP screening and management guidelines
Recommendations for ROP prevention, screening and management	

ROP, retinopathy of prematurity.

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…. I didn't know about the management right from medical training, but I heard from the doctor when he was training us… Health Worker 6

Some (3 out of 8) health workers were aware of the weight criteria of preterm infants with the potential of developing ROP. Few (2 out of 8) recognised the different ROP stages that can occur among the preterm infants affected, highlighting stages from 1 to 5. However, those who knew the stages could not succinctly describe the pathological changes occurring during these stages.

……The baby must be preterm, and with a birthweight less than 1.5kg (1500g), a baby born less than that is a suspect candidate for ROP. Then also, infants who are put on oxygen are a candidate for prematurity……[]……Then there are also stages. They are put according to the stages. There are stages 1,2,3,4,5, but from stage 1 to stage 3, I think the treatment is just observation. Then when the ridge has formed already, that kind of separation is supposed to be for treatment to prevent blindness…… Health worker 4

Subtheme iii: witchcraft and ROP

Some health workers explained that ROP was perceived by locals as a condition arising from cultural practices and that it was associated with witchcraft.

…Well, here in Hoima, they have the so-called *bihara* thing. It is like local witchcraft, so they keep on saying, no they gave my child bihara for the eyes, for the abdomen, and some end up going to those people [witch doctors/traditional healers] and then you realise they can't help…. Health worker 1

THEME 2: CHALLENGES AND LIMITATIONS IN THE IMPLEMENTATION OF THE ROP SCREENING PROGRAMME

Health workers highlighted multiple challenges hindering the effective management of ROP at the facility. Two subthemes emerged from this: ROP screening equipment and Human resources for health.

Subtheme i: ROP screening equipment

Health workers noted the absence of ROP screening equipment, such as screening cameras, an oxygen blender and other accessories. They reported that the lack of these resources significantly impacted the ROP screening process and programmes at the facility.

… We do not have trained staff and equipment for ROP management…[]…even the ophthalmology team doesn't have equipment…[]….and if we don't have the equipment, we can't diagnose. so, if we have to send patients to Kampala (About 200km from the hospital), it is a challenge for them too, and they will not go…. Health worker 1

….The blended oxygen. These infants usually come in distress, and we must manage them for a long time on oxygen, and yet we do not have the blended oxygen. Still, it is a challenge…[]… We must use normal saline bottles for the infants on CPAP. We also use our usual Rwenzori water bottles because we must improvise since we do not have the equipment. Also, sometimes we do not have enough oxygen cylinders, so we use the Y connectors and connect many infants to one cylinder…[]…we do not have a blender that can hold the oxygen suitable for these preterm infants, so you find we are giving them oxygen directly, but at what quantity? This is a resource limitation that still requires better intervention. … Health worker 7

Subtheme ii: human resources for ROP screening

Health workers reported the absence of ROP-trained health workers at the hospital, such as paediatric ophthalmologists, neonatal nurses and neonatologists. This also significantly impacted ROP screening at the hospital.

The staffing is limited, especially in the ward, and we cover different duties…[]…if a nurse comes on duty, they should finish 8 hours and hand it over; sometimes, they go an extra mile and cover the full day. By the time you get back home, you are exhausted. So that's where you find you must cover a whole day…[]…The ophthalmologist should also be specifically allocated to the NICU to manage ROP because, every day, new infants come in and others go out. So, if we do not have a specific person to manage the ROP, sometimes it is challenging …. Health worker 7

….The facility must enrol an ophthalmologist to screen the infants around because currently, we do not have an ophthalmologist, and this is a limitation for the ROP screening…. Health worker 8

Additionally, some health workers suggested that the perceptions around ROP of the parents and caretakers of preterm infants affected by it may reduce their health-seeking behaviours, which disrupts the intervention process and hence effective management.

…Some of the parents believe in rituals. For example, if you tell a parent about the baby's condition but don't recommend that they urgently seek health management and treatment, that parent will assume that the baby's blindness is due to some bad omen. Maybe someone bewitched that baby…. Health worker 3

…Yeah, like any other condition, when you diagnose the condition, some people may associate it

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with witchcraft. Some may think that I was bewitched when I was pregnant, and maybe that is why it has come out like that…[]….As far as treatment is concerned, some people may advocate for herbs. That when we put in the eyes, that thing will disappear…. Health worker 4

……There are diverse cultural beliefs concerning neonatal conditions among caretakers; for example, sometimes, the parents may think that maybe the co-wife or maybe the aunty did something to the baby, and that's what is causing the problem with the eyes. So that may also bias the parents' perception about symptoms of ROP… Health worker 6

Health workers described poor referral mechanisms and follow-up infrastructure within the healthcare system, further disrupting ROP management. Moreover, expert health workers being in the central business district made the management of patients in the regional and peripheral areas more difficult.

…The referrals can be done, but now, the specific people who are trained in ROP in the facility where we are to refer to are limited or not there…[]…we can refer, but as we are talking, we need more experts…. Health worker 3

…The referral system we have is not as good as desired. Sometimes, like the ambulance, the patients contribute the fuel. Sometimes, they don't have the money for the fuel…[]…We found one ROP case and told them to go for treatment in Mulago. Unfortunately, the patient got lost and came back. At first, I thought she had not reached, but when I saw the medical form five for Mulago, I knew she had reached. She narrated: "They told me to go back to some ward to pick a file, and it proved to be a long process, and yet where I was supposed to go was different, so I came back…. Health worker 2

THEME 3: TRAINING AND GUIDELINES FOR ROP SCREENING AND TREATMENT

Two subthemes, ROP training and ROP screening guidelines, emerged under this major theme.

Subtheme i: ROP training

The participants suggested a range of improvements to enhance their knowledge about ROP. They said continuous training could help improve their knowledge and expertise, and continual refresher courses are necessary to keep them updated with any developments in the field. Furthermore, it was suggested that other stakeholders, such as organisations prioritising eye health, must continue to train health workers about early childhood blindness and ROP. Some recommended enhancing training in other peripheral facilities handling preterm infants to quickly identify the candidates for ROP and easily make the appropriate referrals.

….But we can have continuous training and refresher courses, and we can keep training to see whether people are up to date…. Health worker 2

…We were having blindness in infants, but we didn't know much about ROP and how it can cause blindness. So now, having information from the training and the institutions looking at preventing childhood blindness can help us better understand and manage the condition… Health worker 3

……Staff have to be trained in ROP management. ROP management is not about giving the treatment; it starts with screening, examination, and diagnosis. Health workers lack knowledge, so they need training in that… and "…we need knowledge, training, how to suspect and refer to the eye unit for screening. Even those in the health centres, need to be sensitised. As we have said, a child born with a weight less than 1.5kg should be screened for that. We need to create awareness in all health facilities…… Health worker 4

….Refresher training and resources that help us continue with this knowledge are necessary for us health workers. For example, we have assessment charts around the wards of common conditions…[]…providing those charts, desktop placards, and also updating our various tools, for example, the clerkship files, is key in helping us understand ROP…we are using a 2019 version; maybe the current version can have something that can help us evaluate the a child for ROP……. Health worker 6

Subtheme ii: guidelines for ROP screening and management

Health workers described an absence of ROP guidelines at both the facility and in Uganda. They would manage patients according to material written in international textbooks which may not be generalisable to the local situation. Some health workers mentioned that they had never heard of ROP guidelines and were unsure of whether Uganda had any. While they pointed out that there were national guidelines instructing the screening, diagnosis and management of other conditions such as malaria and HIV, there was an insufficiency in guidance for ROP. Without this, their only option when encountering such cases was a referral to a specialist centre for further management.

…there is no specific protocol for ROP. There are guidelines for managing malaria and other conditions, but no guidelines currently exist for ROP. We follow according to the staging just written in the

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books for ophthalmology…. and …But now, there are no proper guidelines for treating this in the national system. Yes, we refer to an ophthalmologist in Mulago (about 200km from the hospital), but now the attendant may get stuck with the patient… Health worker 4

……ever since I started practicing medicine and working in the NICU, I have not heard about these ROP guidelines, and yet the ministry keeps developing guidelines for other conditions….the country needs to work upon them to help these preterm infants strategically…. Health worker 5

….I have not encountered those ROP guidelines, so I do not know any… Health worker 8

THEME 4: RECOMMENDATIONS FOR ROP PREVENTION SCREENING AND MANAGEMENT

Participants gave various recommendations for enhancing the screening and management of ROP among preterm infants. For example, creating locum vacancies for the appropriately trained personnel in facilities lacking such expertise, or training current staff on ROP screening and management. The health workers also recommended acquiring equipment facilitating the management of ROP.

…I think if we can get a qualified person to come more often, maybe we can identify preterm infants at risk…[]….Maybe if we can also have the equipment at Hoima Regional Referral Hospital and train the staff on how to use that equipment, that can improve the management of these patients…. Health worker 1

…More training, equipment provision and the human resource that would empower us to be much better… Health worker 3

….Training, staff have to be trained in managing ROP. Management is not about giving the treatment; it starts with screening, examination, and diagnosis. Health workers lack knowledge, so they need training in that…[]…we need to have a CMEs about ROP because the health workers do not know about it in the entire hospital… Health worker 4

Some health workers recommended having in-country guidelines specific to the Ugandan setting borrowing from the international standards. These could be based on the local conditions and situation in the different health facilities handling these infants, such as the availability of human resources and equipment used in ROP screening.

……But then there is a need to tailor the standard to what is around. If I know what I am supposed to do, I can often use what is around me to try to achieve the standard. But sometimes, if the very system that knows the standard tries to design the protocol that is setting specific, I think it would be better….[]… Because I can do something effective out of improvising, but if the person is affected by the absence of the equipment, they may have nothing to achieve the standard. So we can have further training and resourcing of the unit that uses what we have in our low setting to achieve the standard…… Health worker 6

Health workers were concerned about the community's lack of knowledge of ROP. They recommended different community sensitisation programmes to counter the myths and beliefs about the condition and help narrow the knowledge gap. Health workers believe that the community may appropriately seek health interventions if they are informed about ROP and the associated risk factors, screening and diagnosis.

……we can go to the radio and announce and tell them that every child who is born with this weight, less than 1.5kg, should be brought to the hospital for ROP screening. All those infants must be screened for every woman who produces a preterm, less than 34 completed weeks. People will understand the problem…… Health worker 4

"……We may also need radio talk shows to sensitise the community because most people listen to the radio to get information. Then, there are also those specific days like eye week; we can also create a particular awareness of ROP during that period so that people are aware of it. Because the more significant the awareness, the better the management…. Health worker 5

…We should make everyone alert about ROP, the community also must be sensitised and these play a crucial role in the management, especially among the parents of preterm infants… Health worker 6

……I have not heard that concern being communicated among communities, and even when you tune in to radio stations, I have not heard it being mentioned anywhere. So our awareness about the condition is still very low, and even nothing is talked about, yet this is a condition that can easily lead to childhood blindness…… Health worker 8

DISCUSSION

Low-income and middle-income countries (LMICs) like Uganda are facing a rising epidemic of ROP which challenges healthcare systems in aspects such as screening,

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management and follow-up of affected preterm infants.[16 17] It is important that the respective healthcare systems overcome these challenges, seeking the appropriate equipment, trained staff and guidelines. Overall, health workers in this study reported limited knowledge and awareness about ROP. Most health workers were unaware of the condition's staging, risk factors, diagnosis and management. The evidence provided in this study corresponds with the findings from a cross-sectional study from Uganda, which showed limited awareness of ROP among caregivers and medical professionals.[18] More evidence demonstrated limited understanding of the condition among nurses and paediatricians, warranting further capacity building.[19 20] Findings from our study show the need for continuous training through ward teachings and Continuous Medical Education sessions along with refresher courses in ROP. This training can enhance knowledge and skills about ROP among the health workers handling preterm infants.[8 21–23] They can offer up-to-date information concerning the management, screening criteria and different innovations, especially from high-income countries. A mixed-methods study from Uganda further demonstrated that just 24.6% of medical professionals across two national referral hospitals in Uganda had received ROP training. These results are minimal and confirm the need for regular training.[18] The absence of comprehensive training packages for ROP for the different cadres in Uganda's healthcare system, such as neonatal nurses and OCOs, creates barriers to the effective management of ROP. Coupling ROP training with ROP management guidelines would benefit health workers in different facilities nationwide in effectively managing ROP.

The absence of national ROP management and prevention guidelines in countries across SSA, including Uganda, means that health workers have no standards to follow for treating patients with ROP.[10] Kenya and South Africa developed national ROP guidelines for primary and secondary prevention.[4] With the improvement of neonatal care services across some of these nations, preterm infant survival has progressively improved.[24–27] While there is survival improvement, certain risk factors such as ROP identification necessitate keen attention to minimise the risk of early childhood blindness. We recommend enhancing strategies for in-country ROP guidelines by collating multiple data from different facilities attending to preterm infants to improve neonatal outcomes and minimise the risk of early childhood blindness.

The health workers also noted the absence of equipment to manage preterm infants, such as oxygen blenders and ROP screening equipment. Approximately 60% of neonatal units in SSA offered blended oxygen to different preterm infants, and most NICU units lacked oxygen monitoring for these infants.[28–30] The administration of combined oxygen and utilisation of saturation targets is protective against ROP among preterm infants in multiple settings. These warrant an urgent need for implementation at the facility and other regional referral hospitals nationwide to improve neonatal outcomes.[31 32] The absence of equipment offers an avenue for innovation to develop customised equipment for local settings. Equipment, such as screening devices, can be designed to counter their shortage and the higher costs of procuring the current equipment on the international market.

Health workers recommended training local and available health workers in ROP management, such as nurses, midwives and OCOs. This phenomenon, known as task shifting, could be relevant in rural areas within Uganda which have limited human resources, such as ophthalmologists, neonatologists and paediatric ophthalmologists with ROP expertise.[33] The recommendation agrees with the findings from a qualitative study that emphasised the different benefits of task shifting in settings with under-resourced specialties.[34] Task-shifting in a specialised condition like ROP requires adequate and coordinated training about the different concepts, such as the screening of ROP.[35] This training can often be coupled with routine supervision of the trainees by an expert ophthalmologist to evaluate its effectiveness in knowledge and skills transfer.[36] Uganda has a training programme for OCOs, a lower cadre of ophthalmologists who can do essential eye services, such as visual acuity screening. OCOs can also identify basic eye conditions and refer patients where necessary.[37] OCOs could be trained in the different aspects of ROP as they are distributed countrywide.[34 37] However, comprehensive information is absent concerning task shifting of different ophthalmology services among OCOs beyond their scope and curriculum, such as ROP screening and management. The absence of this critical information can impact the delivery of these highly specialised services to populations that require them. Overall, this shows how individual, institutional and national factors determine the different perspectives of health workers about ROP identification and management. Addressing these factors at the appropriate level is crucial to enhancing the capacity of health workers in managing ROP in Uganda.

Limitations

The study had a number of limitations, including the low number of health workers in the NICU of interest. The low recruitment of health workers at the facility was an administrative and staffing limitation arising from the limited resource envelope to cover the wages of new employees from the country's Health Service Commission. This limitation was beyond the researchers' control and may have constrained the diversity of perspectives despite achieving saturation. The absence of opinions from ROP experts at the facility, including a paediatrician, neonatologist and paediatric ophthalmologists, limited the collection of expert insights regarding ROP. These opinions could have enriched our findings, particularly regarding decision-making during ROP diagnosis and interprofessional and interdepartmental collaboration. This was a single-site study since it is the only facility in the

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region with a NICU. While it was the only facility in the region with a functioning NICU, the single site limits the generalisability of the findings to other settings. However, we believe that these results could reflect the situation in other regional referral hospitals across the country.

CONCLUSION AND RECOMMENDATIONS

This study provides comprehensive perspectives about ROP from health workers working in the NICU of a regional referral hospital. This study highlights key impediments to the successful management of ROP in HRRH's NICU, including inadequate knowledge about ROP among health workers, the absence of ROP guidelines, screening equipment and specialised health workers such as paediatric ophthalmologists, neonatologists and neonatal nurses with ROP training to manage the condition at the facility. Notably, information obtained from this study could represent the situation in the different regional referral facilities across Uganda that serve multitudes of preterm infants. We recommend the implementation of public awareness campaigns about ROP in the Bunyoro region and within Uganda. These campaigns must target the public, especially the parents of preterm infants. Enhancing their awareness can improve the health-seeking behaviours among the parents, thus enabling timely interventions.

We recommend drafting different ROP guides and training material to enhance the knowledge and skills of health workers working with preterm infants. The study further highlights workable recommendations from the health workers' perspective, such as establishing in-country ROP guidelines and continuous knowledge translations. We recommend multidisciplinary collaboration among professional experts and other health workers involved in managing preterm infants, such as midwives, neonatal nurses, hospital pharmacists, medical doctors and paediatricians.

We propose another evaluation among health administrators, such as hospital administrators, district health officers, commissioners of health and the different ministers responsible for neonatal health in Uganda. Their insights can offer a concrete position concerning ROP in the country, warranting policy change and approaches to managing the condition. We also recommend a country-wide evaluation of the incidence and prevalence of the condition to establish nation-wide data. This can inform further management, planning and policy development strategies in Uganda that can further be adopted by other LMICs.

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REFERENCES

1 Kirby RP, Malik ANJ, Palamountain KM, *et al*. Improved screening of retinopathy of prematurity (ROP): development of a target product profile (TPP) for resource-limited settings. *BMJ Open Ophthalmol* 2023;8:e001197.
2 Hong EH, Shin YU, Cho H. Retinopathy of prematurity: a review of epidemiology and current treatment strategies. *Clin Exp Pediatr* 2022;65:115–26.

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3 García H, Villasis-Keever MA, Zavala-Vargas G, *et al*. Global Prevalence and Severity of Retinopathy of Prematurity over the Last Four Decades (1985-2021): A Systematic Review and Meta-Analysis. *Arch Med Res* 2024;55:102967.
4 Wang D, Duke R, Chan RP, *et al*. Retinopathy of prematurity in Africa: a systematic review. *Ophthalmic Epidemiol* 2019;26:223–30.
5 Ezeanosike OB, Ezeanosike E, Akamike IC, *et al*. Prevalence and risk factors of retinopathy of prematurity in Africa: A systematic review and meta-analysis. *Niger J Paediatr* 2021;48:114–27.
6 Ndyabawe I, Namiiro F, Muhumuza AT, *et al*. Prevalence and pattern of retinopathy of prematurity at two national referral hospitals in Uganda: a cross-sectional study. *BMC Ophthalmol* 2023;23:478.
7 Dogra MR, Katoch D, Dogra M. An Update on Retinopathy of Prematurity (ROP). *Indian J Pediatr* 2017;84:930–6.
8 Darlow BA. Primary prevention of ROP: more can be done in all settings. *Expert Rev Ophthalmol* 2023;18:177–91.
9 Smith AF, Sadeq A, Kinzel E, *et al*. A Systematic Review of Economic Evaluations Conducted for Interventions to Screen, Treat, and Manage Retinopathy of Prematurity (ROP) in the United States, United Kingdom, and Canada. *Ophthalmic Epidemiol* 2023;30:113–20.
10 Gilbert C, Malik ANJ, Nahar N, *et al*. Epidemiology of ROP update - Africa is the new frontier. *Semin Perinatol* 2019;43:317–22.
11 Manfredo MJ, Teel TL, Gavin MC, *et al*. Considerations in representing human individuals in social-ecological models. Understanding society and natural resources: Forging new strands of integration across the social sciences. 2014;137–58.
12 McCormack L, Thomas V, Lewis MA, *et al*. Improving low health literacy and patient engagement: A social ecological approach. *Patient Educ Couns* 2017;100:8–13.
13 Kaudha R, Amanya R, Kakuru D, *et al*. Anemia in HIV Patients Attending Highly Active Antiretroviral Therapy Clinic at Hoima Regional Referral Hospital: Prevalence, Morphological Classification, and Associated Factors. *HIV AIDS (Auckl)* 2023;15:621–32.
14 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
15 Coetzee B, Kagee A, Vermeulen N. Structural barriers to adherence to antiretroviral therapy in a resource-constrained setting: the perspectives of health care providers. *AIDS Care* 2011;23:146–51.
16 Senjam SS, Chandra P. Retinopathy of prematurity: Addressing the emerging burden in developing countries. *J Family Med Prim Care* 2020;9:2600–5.
17 Ahmed I, Hoyek S, Patel NA. Global Disparities in Retinopathy of Prematurity: A Literature Review. *Semin Ophthalmol* 2023;38:151–7.
18 Lusobya RC, Atukunda I, Semulimi AW, *et al*. Knowledge, Attitudes and Practices of Health Workers and Caregivers Towards Retinopathy of Prematurity in Uganda: A Mixed-Methods Study. *Public Health Chall* 2024;3:e208.
19 Sankar BK, Amin H, Riaz K, *et al*. Retinopathy of Prematurity: Nursing Perspective. *JCDR* 2021;15.
20 Köse S, Kıvrak G. Knowledge Levels of Neonatal Intensive Care Unit Nurses Regarding Retinopathy and Examination Process. *Balıkesir Sağlık Bilimleri Dergisi* 2024;13:368–74.
21 Thuileiphy T, Joshi P, Dolma Y, *et al*. A descriptive survey on knowledge gap related to retinopathy of prematurity and its prevention and management among nurses in a tertiary care hospital. *Indian J Ophthalmol (Poona City)* 2021;69:2122–5.
22 Raj S, Kumar P. Development and validation of education materials to reduce childhood blindness due to retinopathy of prematurity. *J Educ Health Promot* 2021;10:342.
23 Sankar BK, Marakkar RK, Varghese S. Effectiveness of Developmentally Supportive Education Program on Nursing Knowledge of Retinopathy of Prematurity in Neonatal Intensive Care Unit. *Iran J Nurs Midwifery Res* 2022;27:67–70.
24 Achan J, Wanzira H, Mpimbaza A, *et al*. Improving the quality of neonatal data capture and clinical care at a tertiary-care hospital in Uganda through enhanced surveillance, training and mentorship. *Paediatr Int Child Health* 2020;40:92–104.
25 Waiswa P, Wanduru P, Okuga M, *et al*. Institutionalizing a Regional Model for Improving Quality of Newborn Care at Birth Across Hospitals in Eastern Uganda: A 4-Year Story. *Glob Health Sci Pract* 2021;9:365–78.
26 Ouma PO, Malla L, Wachira BW, *et al*. Geospatial mapping of timely access to inpatient neonatal care and its relationship to neonatal mortality in Kenya. *PLOS Glob Public Health* 2022;2:e0000216.
27 Tuti T, Aluvaala J, Chelangat D, *et al*. Improving in-patient neonatal data quality as a pre-requisite for monitoring and improving quality of care at scale: A multisite retrospective cohort study in Kenya. *PLOS Glob Public Health* 2022;2:e0000673.
28 Lloyd T, Isenberg S, Lambert SR. Current management of retinopathy of prematurity in sub-Saharan Africa. *J AAPOS* 2020;24:151.
29 Campbell JP, Singh P, Redd TK, *et al*. Applications of Artificial Intelligence for Retinopathy of Prematurity Screening. *Pediatrics* 2021;147:e2020016618.
30 Nakibuuka V, Vaucher YE, Namakula L, *et al*. The impact of a multidisciplinary intervention to reduce severe retinopathy of prematurity in Kampala, Uganda. *J Perinatol* 2025;45:208–12.
31 Colaizy TT, Longmuir S, Gertsch K, *et al*. Use of a Supplemental Oxygen Protocol to Suppress Progression of Retinopathy of Prematurity. *Invest Ophthalmol Vis Sci* 2017;58:887.
32 Mantena S, Burke TF. Oxygen Blending is Urgently Needed in Resource-Limited Settings. *J Pediatr* 2021;237:288–91.
33 Palmer JJ, Chinanayi F, Gilbert A, *et al*. Mapping human resources for eye health in 21 countries of sub-Saharan Africa: current progress towards VISION 2020. *Hum Resour Health* 2014;12:44:1–6:.
34 Pente V, Bechange S, Jolley E, *et al*. Task-shifting eye care to ophthalmic community health officers (OCHO) in Sierra Leone: A qualitative study. *J Glob Health* 2021;11:07001.
35 Okyere E, Mwanri L, Ward P. Is task-shifting a solution to the health workers' shortage in Northern Ghana? *PLoS One* 2017;12:e0174631.
36 Resnikoff S, Lansingh VC, Washburn L, *et al*. Estimated number of ophthalmologists worldwide (International Council of Ophthalmology update): will we meet the needs? *Br J Ophthalmol* 2020;104:588–92.
37 Magyezi J, Arunga S. Eye care where there are no ophthalmologists: the Uganda experience. *Community Eye Health* 2020;33:48–50.

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