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COMMENTARY

The future of data management for pediatric cataract

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Cataract is a leading cause of blindness in children worldwide. Blindness can be treated with effective surgery, but in low-resource settings this treatment can be difficult to access. In addition, positive outcomes of the surgery are heavily dependent on comprehensive postoperative care. To date in Nigeria and many other low-resource countries, robust electronic data-management systems that help facility teams to manage their patient data, especially when it comes to tracking children for follow-up visits after surgery, have either yet to be put into place or are in place but have yet to be refined to respond to the specific needs of eye care programs. Sightsavers has worked with multiple state ministries in Nigeria to set up and test a system that responds to those needs.

Keywords: cataract, data, HSS, ophthalmology, pediatrics, systems.

Introduction

Cataract occurs when changes in the lens of the eye cause it to become less transparent, resulting in cloudy or foggy vision. The disease primarily affects older adults but there are also pediatric cataracts, which can present at birth or develop later in childhood.[1] Pediatric cataract is the most common cause of childhood blindness worldwide, with up to 75% of cases occurring in developing countries.[2] Several studies conducted in Nigeria, Tanzania and Ethiopia provided estimates on the prevalence of childhood cataract, ranging from 0.32 to 2.05 per 10 000 children. The global estimates range from 0.32 to 22.9 per 10 000 children.[3] If the condition is not diagnosed and treated early on it can cause irreversible damage to eyesight, with severe consequences for child development and learning.[4,5] It is therefore critical to identify and effectively manage childhood cataracts as early as possible.

Childhood cataract management, however, is laborious and requires long-term contact and multiple follow-up appointments with the patient.[6] Frequent postoperative care and management are necessary to achieve a good outcome as postoperated children may develop mid- to long-term complications, including amblyopia, glaucoma, uncorrected refractive errors and posterior capsular opacities that can result in visual impairment and blindness.[7]

Follow-up appointments are timed at 1 d, 1 and 6 wk initially, and every 3 mo thereafter to monitor response to treatment. Patients in low-resource countries, however, are often lost to these follow-ups after surgery.[8] The proportion of children that return to the facility tends to decrease with each follow-up period; studies have shown that up to 30% of children do not show up for their 3-mo postoperative follow-up. Some of the reasons contributing to the poor follow-up rate include a lack of parental awareness, the long distances parents would have to travel and female gender of the patient.[9] In addition, there are challenges to monitoring pediatric surgical outcomes, which are usually determined by the skill of the surgeon, the type of cataract, the age of the children at presentation and the time of the surgery.[10]

In Nigeria, pediatric cataracts are managed in child eye health tertiary facilities (CEHTFs), which are the highest level centers responsible for the provision of specialized surgical services for children. The facilities deploy paper-based systems to record preoperative and postoperative findings and use follow-up appointment slips. It has been observed that parents often find it difficult to understand the importance of these slips and can easily forget their appointment dates.

One way to improve the quality of care and surgical outcomes is to improve data-management systems, providing facility teams with a way to track pediatric cataract patients throughout their entire management cycle, monitor surgical outcomes and improve communication with parents. Concurrently, many trachoma programs in endemic countries are using an application called the TT Tracker to track patients with trachomatous trichiasis (TT), the late blinding stage of the neglected tropical disease

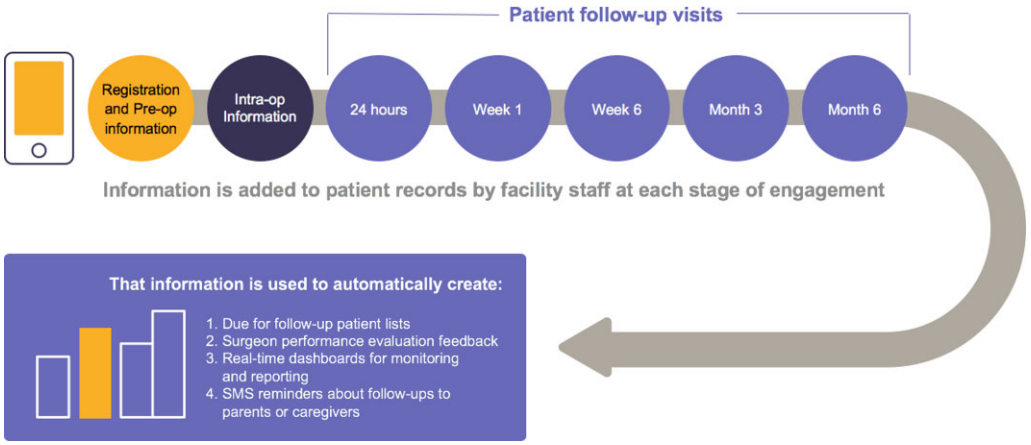

Figure 1. The CataTrack system.

trachoma.[11] Tracking of patients begins at the point of registration and surgery and continues through each patient's follow-up cycle. Nigeria is one of the countries that has successfully integrated the use of the TT Tracker into its trachoma elimination program. Recognizing similarities between managing TT and pediatric cataract patients, in 2019, Sightsavers, the Nigerian CEHTFs and the state ministries of health in Kaduna and Sokoto began working together to repurpose the TT tracking system to be used in the pediatric cataract program. Although the same technologies were used (see more below), this repurposing included changing data-collection forms to reflect those from the pediatric cataract program along with a consultative process to determine specific roles, reports and analysis that needed to be put in place. Finally, all support and training materials were rebranded and made to reflect the new system. The system, called CataTrack, was finalized in early 2020 (Figure 1).

CataTrack system

The facilities are issued tablets, where staff—mainly medical record clerks and pediatric ophthalmologists—are asked to enter:

- Registration and preoperative information: demographic and contact information, visual acuity, intraocular pressure, systemic abnormalities, comorbid eye conditions, biometry, diagnosis and consent.
- Intraoperative information: surgeon information, biometry and any related surgery complications.
- Patient follow-up visits (24 h, 1 and 6 wk, 3 and 6 mo): visual acuity, examination findings in the anterior chamber, posterior segment, additional surgical procedures and refraction with best corrected visual acuity (6 wk onwards).

Based on the information collected, reports then include:

- Patient follow-up lists: these lists are available on facility devices (tablet) or through e-mail. The lists are automatically generated from the fixed follow-up schedule and patients requiring follow-up appointments are indicated, with their location and contact information included. Lists are automatically updated (i.e. when a follow-up appointment takes place and associated data are entered into the system, the patient is then removed from that particular follow-up list).
- Surgical performance evaluation: personal performance reports are e-mailed directly to surgeons. Supervisors are also e-mailed surgery performance assessments, so they know when additional training is needed.
- Real-time, intuitive reports: an online data visualization tool analyzes aggregate data automatically. There are three dashboards: (pre/intra) operative outcomes; follow-up completion and complications; and a data quality area, where potentially erroneous data are flagged (Figure 2).

The CataTrack system also includes a short message service (SMS) component, where SMS messages are automatically sent to the child's main contact (parent, relative, village head, community volunteer, etc.), explaining that the patient needs to come in for each follow-up visit. Messages go out as reminders for each follow-up based on the fixed follow-up schedule. At registration, the preferred language is documented (Hausa or English) for the SMS. It is expected that these reminder messages going directly to the contact provided will increase follow-up rates with no additional effort from facility teams. Facility teams, however, cannot rely on these SMS messages as the only communication with patients: telephone numbers provided on the aforementioned patient follow-up lists can also be used. Although the SMS messages are sent to one telephone number, a second telephone number is collected at registration so that these telephone calls can be successfully made, as many people have more than one SIM card, or may want to enter a local or community leader as a back-up contact.

All data are owned by the state ministries of health. CataTrack uses the same technologies as the TT Tracker, with CommCare[12] as a data-collection tool and Metabase[13] as a data-visualization tool. CommCare can be integrated with national health information systems to automatically update chosen indicators, although during the starting phase of system use this was not done.

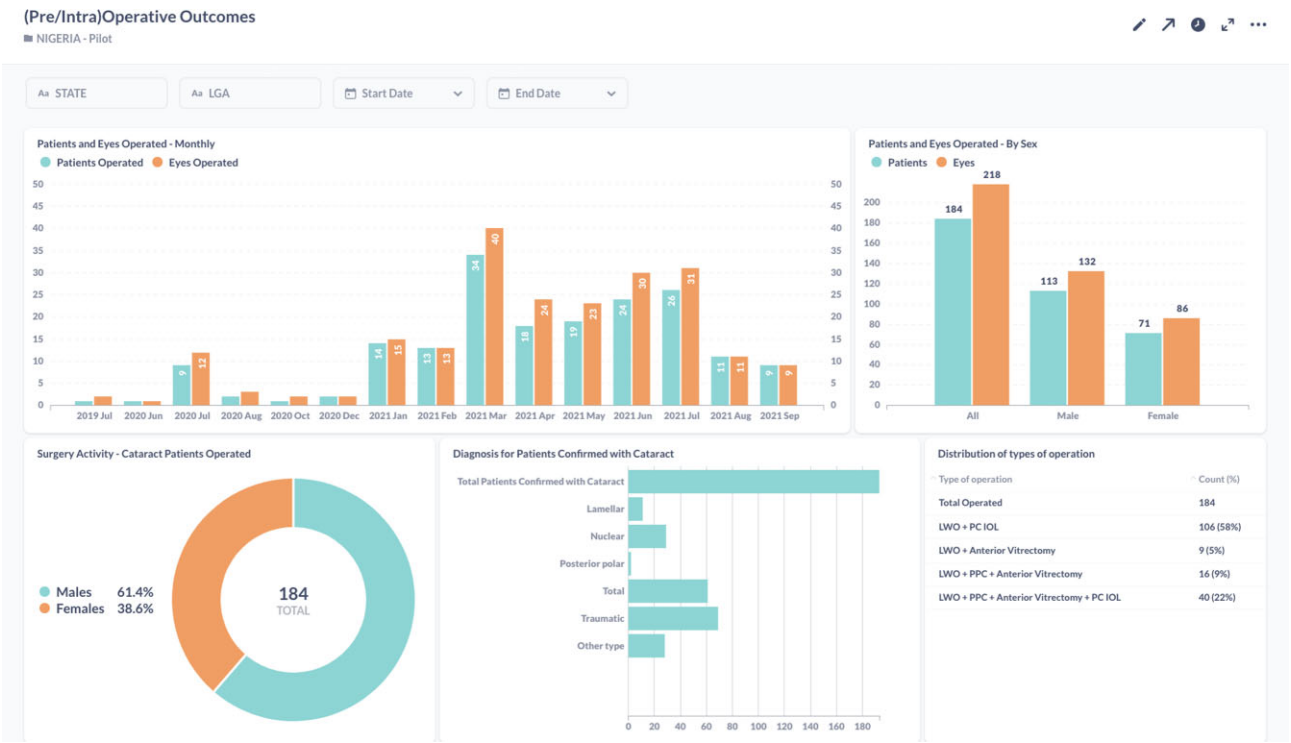

Figure 2. CataTrack data visualisation dashboard example.

Experience to date

Training took place in the CEHTFs in Kaduna and Sokoto states, two in total, and, after a pause in activities due to COVID-19 restrictions, data collection resumed in early 2021. The initial training takes 2 d and covers concepts, roles, uploading onto the app itself and accessing/reading reports. Participants have varying levels of experience with technology, but in general the system is intuitive and trainees learn quickly.

Given that CataTrack is used in CEHTFs, we have not experienced any issues or delays from power cuts or lack of electricity, as power back-ups are in place in the case of power failure from the national grid.

Support is now ongoing through regular contact and review meetings. Feedback has been given to facilities on common data-entry errors identified in the system, and on changes in visual outcome by comparing preoperative and postoperative visual acuity after the 3- and 6-mo follow-up visits. Follow-up rates are reviewed to understand the proportion of children who returned for follow-ups, and if it was prompted by the SMS reminders. Detailed analysis of the data has not yet been commissioned, but initial review shows significant improvement in the uptake of services and the rate of follow-up. Complications recorded by the facilities are also discussed to facilitate quality improvement in the management of patients.

As with any new system, this is an iterative process and feedback loops will remain open as we move ahead. Some examples of changes we have made thus far based on user feedback are around flexibility on editing follow-up dates, changes on the dashboard to compare visual outcomes and inclusion of additional indicators on systemic evaluations. Additional training is also being planned on data use. These sessions will focus on the essential steps beyond data collection itself, making sure that facility staff and supervisors take full advantage of the system to contact patients on follow-up due dates, as well as actively reviewing surgical outcomes: taking action so they improve over time.

Finally, the Sightsavers team is in the process of standardizing reports in the system, saving facility staff time, as they will be able to directly download all of the monthly and quarterly reports they need to produce.

Meeting the demand of eye health programs: next steps

The WHO argues that 'a well-functioning health information system is one that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status'.[14] We view the CataTrack system as a bridge to help many countries reach this goal. At present, national electronic medical record systems are either not in place or do not yet meet the demands of national and subnational eye care programs. CataTrack offers eye health programs and healthcare providers a way to manage their data and improve patient care and outcomes through having access to timely, accessible information.

Although currently covered by Sightsavers funding, the system using CommCare is around $3000 per annum; these costs could be covered by the country over time, or, as stated above,

CataTrack can be seen as a bridge to establish a more robust electronic medical record system or health management information system (HMIS) that includes tracking of individuals. As seen with the TT Tracker, which is used in multiple countries, the use of CataTrack is replicable if countries have a desire for an improved system and adequately support the data collection and use, and where government or partner support is available for the system and training.

Moving ahead, Sightsavers aims to scale up the use of this system in Nigeria and other countries to manage first, pediatric, then later, with minor changes to the system, age-related cataracts. At the same time we will work to support improvements to national systems so they are able to take over the role that CataTrack currently plays. In Nigeria specifically, we will work to integrate CataTrack with the country's HMIS, housed in District Health Information Software 2 (DHIS2), so that certain indicators can be pulled directly from the system. There is also a considerable opportunity to take functionality from and lessons learned through the use of CataTrack to improve the current electronic medical record systems being used in some facilities, making them more robust in tracking and improving the quality of eye care services. The goal remains for facility teams to prioritize their data analysis and use skills—leading to improvements in their program delivery—and to help strengthen nationally managed data systems that take into account the needs of eye health programs.

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