



Case Study:

International Team Gives Caregiver Education in Democratic Republic of the Congo

SIG 17: Global Issues in Communication Sciences and Related Disorders

Summary

When visiting a village school and outpatient rehabilitation clinic in the Democratic Republic of the Congo (DRC), a team of professionals from the United States worked with their local counterparts to provide training and help patients. One patient was a 6-year-old boy with a complaint of severely reduced expressive language. The team – comprising both US and DRC medical professionals – worked together to create an assessment and treatment plan for the boy. They also provided education and strategies to the boy’s mother.

Patient Info



ETUMBU
6-YEAR OLD

Current Diagnosis:

Severely reduced expressive language

Meet The Team



Audiologist
(team facilitator)



Physician (also
the resident medical
director of CERBC)



SLP #1



SLP #2



Physical therapist
(PT)



Nurse practitioner



CERBC rehabilitation aid



CERBC physiotherapist and translator



Patient



Family

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Background

The Centre for Education and Community Based Rehabilitation (CERBC) is a school and outpatient rehabilitation clinic in Aru, a rural village in the Ituri Nord province of DRC. The school wing of CERBC provides primary, secondary, and vocational education for children who are blind, deaf, and/or have physical and cognitive disabilities. Many of them are unable to attend traditional day schools. The majority of the students have hearing loss caused by meningitis or malaria. Other diagnoses include cerebral palsy, genetic syndromes (including Down syndrome), burn contractures, macular degeneration, and polio. The clinicians at the rehab center also diagnose and treat adult and pediatric patients.

Following two visits to CERBC, an interprofessional practices (IPP) team assembled to target previously identified areas of need. The team consulted with CERBC faculty, teachers, and medical professionals within the community and selected topics for training sessions in a variety of disciplines. The result was a 10-day training clinic. Each morning of the training, all CERBC faculty and visiting clinicians attended a 1-hour lecture presented by members of the visiting IPP team. Afterwards, the visiting clinicians traveled with their CERBC counterparts to the clinic to see patients together.

During this time, a 6-year-old boy named Etumbu arrived at the clinic after a 3-hour moped ride from their remote village with his teenaged mother. Etumbu presented with a complaint of severely reduced expressive language.

Obtaining an adequate medical and developmental case history was challenging, as his mother responded to most questions with one-word answers or stated that she had forgotten. She described a “difficult” birth with labor lasting 2–3 days. She reported that she believed he had functional hearing at birth, and the audiologist confirmed this by conducting oto-acoustic emissions (OAE) testing. Etumbu had not been enrolled in primary school due to his lack of speech.

How They Collaborated

The IPP team met to discuss what types of assessments Etumbu needed. Given the mother’s concerns, the team began with speech and hearing evaluations and were assisted by translators.

The audiologist’s assessment found that Etumbu’s hearing was within normal limits. However, while demonstrating how to assess the patient’s receptive language skills with a picture-pointing task, the SLPs and the rehab aide observed that Etumbu struggled to point to a picture with his right (dominant) hand. By pointing with his left hand, Etumbu revealed comprehension of a good deal of functional vocabulary. However, Etumbu did not follow commands such as “Put the ball next to the elephant.” His expressive language was limited to “Mama,” “Baba,” and “Du-doe” (his sister). Etumbu also displayed significant difficulty copying movements modeled by the rehab aide.

The visiting SLPs and the rehab aide worked with Etumbu by modeling the pronunciation of his name. Then, the team asked his mother to copy the clinician’s use of cues to practice with her son. She was reluctant and shy at first. However, with encouragement from the aide, she successfully used the strategies that she observed.

Following the consultation, the team met again to discuss the assessment findings and create a treatment plan. The PT said that a physical evaluation may be required due to the observed upper-extremity weakness, and the team agreed. The PT evaluated Etumbu and provided caregiver education via a translator. The PT also

How They Collaborated continued

demonstrated to the CERBC physiotherapist specific strengthening and flexibility exercises that were appropriate for Etumbu (e.g., throwing a playground ball). After a team discussion, the CERBC physiotherapist agreed to do a trial with Etumbu to see how he progresses with the exercises.

Due to regional cultural beliefs regarding handedness, caregiver education was required to ensure that Etumbu's family and future teachers understand that functional use of his right hand is unlikely. The team encouraged his family and teachers to support and accept Etumbu's use of his left hand.

The IPP team recommended that Etumbu return to the clinic for continued speech-language therapy and physical therapy services.

Outcome

Due to the family's extreme poverty and remote location, ongoing therapeutic services were not possible. The team met with Etumbu's mother to provide education and strategies and to inform her of the likely diagnosis of cerebral palsy.

Most important, Etumbu's mother understood that her son could hear and comprehend spoken language and that he may also be able to learn to read. She acknowledged that he should begin attending the local primary school. She confirmed that she understood the team's explanation for allowing her son to use his left hand and stated that she planned to continue practicing single-word speech with him.

Ongoing Collaboration

At the conclusion of the 10-day clinic, the visiting clinicians and CERBC faculty reviewed successes and areas for improvement. The CERBC Board of Directors requested that the team plan for similar clinics every other year and recruit two additional members of the IPP team—an occupational therapist (OT) and an ear, nose, and throat surgeon.

Due to civil unrest in eastern DRC, a planned trip has been put on hold. The inability to follow through with the next planned visit highlights the problem of sustainability in this type of setting. However, technology is helping to bridge the gap. The CERBC director is in touch weekly with one of the American SLPs via text message. This communication often revolves around specific cases.

The CERBC director and resident medical director routinely reach out to all of the American members of the clinical team for case questions. The IPP team members regularly discuss telepractice and teletraining options, but they are unable to implement them due to the unreliable Internet connection on the CERBC campus. Team members continue to participate in fundraising initiatives that specifically target sustainable development of the CERBC.

Case Rubric:

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Meet The Team



Audiologist
(team facilitator)



Physician (also
the resident medical
director of CERBC)



SLP #1



SLP #2



**Physical
therapist (PT)**



**Nurse
practitioner**



**CERBC
rehabilitation
aid**



**CERBC
physiotherapist
and translator**



Patient



Family

Continue for more ↓

<p>History and Concerns (Share key information gathered from team)</p>	<p>Obtaining an adequate medical and developmental case history is challenging, as his mother responds to most questions with one-word answers or states that she forgot. She describes a “difficult” birth with labor lasting two to three days. She reports that she believes he had functional hearing, and this was confirmed via Oto-Acoustic Emissions (OAE) testing performed by the Audiologist. Etumbu has not been enrolled in primary school due to his lack of speech.</p>
<p>Assessment Plan (Determine roles/responsibilities for evaluation)</p>	<p>The IPP team meets to discuss what types of assessments Etumbu might need. Given the case history, the team members recommend they start with speech and hearing evaluations, as those were of primary interest to the mother. Translators are required for speech evaluations. The audiologist reports hearing within normal limits.</p>
<p>Assessment Results (Summarize key diagnostic results)</p>	<p>While demonstrating to the rehab aide how to assess the patient’s receptive language skills with a picture-pointing task, the two visiting SLPs and the rehab aide observe unilateral upper extremity weakness, significant enough to make pointing to a picture from an array of three 3x4 inch cards imprecise and effortful with his right (dominant) hand. Etumbu points to the noun named by the rehab aide (in Lingala) with his left hand, revealing comprehension of a good deal of functional Lingala vocabulary including <i>girl, boy, car, goat, table, ball, and elephant</i>. However, Etumbu does not follow novel commands such as “put the ball next to the elephant”. His expressive language is limited to “Mama”, “Baba”, and “Du-doe” (his sister). He has significant difficulty copying labial and lingual movements modeled by the rehab aide (with coaching from the visiting SLP) but does attempt to imitate. He produces reduplicated CV syllable structures ma, ba, da, ta when prompted with tactile cues and modeling. After several attempts, the visiting SLP and the rehab aide working together elicit “EH-BU”, an approximation of his name. His mother copies the clinician’s use of cues to practice with her son. She is reluctant and shy at first, but with encouragement from the CERBC rehab aide, utilizes the strategies she has observed.</p>

IPP Treatment Plan

(Discuss, reflect, and modify recommendations to develop a coordinated plan)

Following the consultation with the SLPs and audiologist, the IPP team meets to briefly discuss the assessment findings and to make a treatment plan. During the team discussion, the upper extremity weakness is mentioned, and the PT expresses that a physical evaluation may be required. The team discusses the pros and cons of such an evaluation given the resources available and concludes that Etumbu requires a physical evaluation. The PT evaluates Etumbu. Due to regional cultural beliefs regarding handedness, caregiver education is required to ensure that Etumbu's family and future teachers understand that functional use of his right hand is unlikely, and they are encouraged to support him using his left hand. This caregiver education is given by the American PT, but translated into Lingala by the Congolese physiotherapist. The PT also demonstrates specific strengthening and flexibility exercises that are appropriate for Etumbu (e.g., throwing a playground ball) to the CERBC physiotherapist. Prior to this training, the CERBC physiotherapist's skills for Etumbu's diagnosis were limited to massage therapy. The CERBC physiotherapist initially states that throwing a ball would not likely result in any functional improvement for Etumbu. However, after team discussion, the CERBC physiotherapist states that he would do a trial with Etumbu to see how he progresses. Further team discussion regarding Etumbu's needs ensues.

The IPP team recommends that Etumbu return to the clinic for continued SLP and PT services.

Treatment Outcomes

(Discuss results of treatment)

Unfortunately, due to the family's extreme poverty and the remote location of Etumbu's home, ongoing therapeutic services are not possible. Clinic funding is not the primary factor—the issue is that his mother is not able to stay away from her work in the fields because that work provides necessary food and income for her family. The teams—consisting of the CERBC rehab aide, the two American SLPs, the CERBC physiotherapist, and the American PT—meet with Etumbu's mother to provide education and strategies as a team as well as to inform her of the likely diagnosis of cerebral palsy. Most importantly, Etumbu's mother demonstrates understanding that her son could hear and understand spoken language and that he may also be able to learn to read. She acknowledges that he should begin attending the local primary school. She is able to repeat back (in Lingala) the team's explanation for allowing her son to use his left hand, and she states that she plans to continue practicing functional single-word speech with him.

Team Follow-Up

(Determine meetings & communication plan)

At the conclusion of the 10-day clinic, the visiting clinicians and CERBC faculty debrief on successes and areas for improvement and/or ongoing need. The CERBC Board of Directors requests that the team **(a)** plan for similar clinics every other year and **(b)** recruit an occupational therapist (OT) and an ear, nose, and throat (ENT) surgeon. Unfortunately, due to civil unrest in Eastern DRC, a planned trip is put on hold. The inability to follow through with the next planned visit highlights the problem of sustainability in this type of setting. However, technology is helping to bridge the gap. The CERBC director is in touch weekly with one of the American SLPs via text message. This communication often revolves around specific cases. The CERBC director (who served as the facilitator on the IPP team) and the CERBC resident medical director (who served as the physician on the IPP team) routinely reach out to all of the American members of the clinical team for case questions. The IPP team members discuss telepractice and teletraining options, but are unable to implement them due to poor reliability of the Internet connection on the CERBC campus. **Also, team members participate in fundraising initiatives that specifically target sustainable development of the CERBC—including the following projects:**

1. Construction of a sound-proof auditory testing room
2. Purchase and transport of a portable audiometer, replacement parts for the clinical audiometer, and purchase and transport of an OAE/auditory brainstem response (ABR) screening device (the only one currently in eastern Congo)
3. Construction of and furnishing of a sewing room for the vocational program in tailoring
4. Purchase and transport of several musical instruments for the visually impaired students' choir/band
5. Funding of tuition for the CERBC resident medical director (who served as the physician on the IPP team) to complete training as an ENT surgeon at Makerere University in Uganda
6. Scholarships for 36 students for room, board, and tuition at CERBC
7. Financial awards for female graduates of the various vocational training programs
8. Construction and maintenance of an on-site well and cistern system, which will provide fresh water to the campus and eliminate the need for dangerous walks to fetch water
9. Funding to bring the CERBC director to two U.S.-based locations: **(a)** to Veteran's Affairs, (Boston, MA) for training and networking and **(b)** to the upcoming ASHA convention

Acknowledgement

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Amanda Hitchins, MS, CCC-SLP
Special Interest Group 17 (SIG 17): Global Issues in Communication Sciences and Related Disorders

Citations

American Speech-Language-Hearing Association. (n.d.). International team gives caregiver education in Democratic Republic of the Congo. <https://www.asha.org/practice/ipe-ipp/case-studies/case-study-10/>

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