

Clinical paediatric neuropsychology in Uganda

Tara Murphy, Bachayaya Akello Pauline, & Nangonzi Josephine

Part 1: Volunteering in Uganda

Tara Murphy

Jamestown Hospital, Health Directorate, Saint Helena, South Atlantic, STSH 1ZZ

During 2018, I had the opportunity to volunteer for ten months at Butabika National Referral Hospital in Kampala, Uganda. Butabika is the only mental health hospital in Uganda.



Figure 1. Butabika National Referral Hospital, Kampala, Uganda (Photo credit: Kirstie Fleetwood).

Regional Referral Hospitals in Uganda also have a small mental health service, usually of 10-40 inpatient beds and long queues of outpatients. However, Butabika is large, typically accommodating about 950 patients, including 30-40 children and young people. The hospital was designed for about 500 patients (Molodynski, Cusack, and Nixon, 2017). As neurological illness and mental health conditions are stigmatized in Uganda, and Africa as a continent (Kaddumukasa, et al. 2018), it will not be a surprise that the hospital itself has quite a reputation. The education system is loosely based on the UK system and school children sit 'O' levels at 15 years and 'A' levels at about 18 years of age. The main language of educated people is English and there are more than 50 other languages spoken across the country.

I worked 2-3 days per week alongside several commitments in the United Kingdom. There was another UK volunteer, Dr Kirstie Fleetwood, Counselling psychologist, and we worked together on many projects. The collaboration was part of the Butabika East London Link (<https://www.butabikaeastlondon.com/>), which often receives funding from THET Partnership for Global health (www.thet.org).

In this article, I describe the neuropsychology related experiences I had during the volunteership. For a description of the broader experience, we have written a piece for *The Psychologist*, which will be published later this year.

Assessment Clinics

In a typical outpatient clinic day, we would assess about 6-8 children. About half of the children had epilepsy and moderate to severe intellectual disability. Other presenting concerns were undiagnosed mild intellectual disability and associated psychological difficulties such as anxiety, depression and self harm. In addition we regularly saw children with autism, psychosomatic conditions, and occasionally tic disorder and obsessive compulsive disorder.

Epilepsy - the common cold of neurology

Epilepsy is quite common in Uganda (Duggan, 2010). However, it is often misunderstood and feared. Stigma surrounds the condition and families often do not know that it is usually treatable. The consequences of this were evident in regular experience of seeing individuals in their late teens that have experienced lifelong epilepsy since early childhood, who had daily seizures (referred to as 'attacks'), intellectual disability, no formal education and limited options for future achievement outside their home family. The most common reason that families came to Butabika hospital with their child with epilepsy was that a neighbour had received helpful input there and recommended it.

As Butabika Hospital is a government funded institution, anti epileptic medication and consultation are free. The only drawback was that the provision and types of medication were limited and often stocks dwindled and ran out for several weeks. However, a detailed history, discussion about possible aetiology (excluding the likelihood of witchcraft as a cause), psychoeducation about 'dos and don'ts' for children with epilepsy (e.g. not riding a bicycle, standing over a fire) was generally well received. Many of the causes appeared to be due to perinatal complications, cerebral malaria and a positive family history.

I observed the importance of the brief psychoeducation that was given at the hospital and wondered how this could be optimized. This led me to apply for a small grant from the Butabika East London Link in order to make a psychoeducational film for service users. We were successful and a filmmaker, Lucia Tambini, from the UK agreed to support the project. We filmed a teenage girl who had been successfully treated for epilepsy and several colleagues talking about the condition. It was interesting to consider how to represent the role of traditional healers within this mainstream medicine perspective without alienating this important community.

From there, we found colleagues to translate the video into several local languages and sign language. We received ten tablets on which to play the video in the outpatient department from an Irish NGO called Camara Education. We have plans to broadcast the film on Ugandan television and put it on the Link website and YouTube, once it is complete. This will be included in article I have co-written that will hopefully be published in The Psychologist later in 2019.

I am not sure about the impact of the film. I am hopeful that it might disseminate useful, practical well informed information about epilepsy to encourage families to attend clinic, challenge stigma (e.g. that epilepsy is caused by a lizard in the brain) and reduce disturbing practices which occur all too often in people with epilepsy.

Peculiarities and lessons learnt

One of the things I noticed in the first two months of working in the children's ward was the clinician's understanding of mild intellectual disability. We regularly saw children who fared reasonably well in primary school (Primary 1-6) but struggled hugely in the transition to secondary education (Senior 1). Often these young people were competent at simple daily living skills of self - care, household chores and communication but more sophisticated activities, schoolwork and social interactions challenged them. In addition, their parents often reported that they did not follow instructions, forgot novel information, found it difficult to learn new skills and struggled with scholastic progress.

The importance of performing well academically is evident in Uganda - this related to parent's hopes for the future of their children. There is stigma from the community when a child is required to repeat a school year once, twice or even three times, which was common in the children who presented to our clinic.

Given that we initially had few cognitive assessment materials, our understanding around the adolescent's cognitive ability was limited and based on informal questioning. Despite reports of strengths with procedural learning and everyday activities these individuals struggled to achieve at the same level as their peers. I used practical tests such as writing their name, numerical exercises, calculating change, asking about practical logical problems (e.g. "What should you do if you see a fire in your neighbour's home?") to assess their abilities. This gave mixed results and I found that my colleagues were often keen to normalize the behaviour far more quickly than I was, but then I didn't have experience of Ugandan teenagers, and they had limited experience of the concept and presentation of mild intellectual disability. My sense was that we needed an objective measure of cognitive function.

The only paediatric tests that I could find in the literature that have been validated in Uganda are the Kaufman Assessment Battery for Children; Test of Variables of Attention; Bruininks-Oseretsky Test of Motor Proficiency; Behavior Rating Inventory for Executive Function (Bangirana et al, 2009; Chernoff et al, 2018) which none of the trainee psychologists had experience of using or had any access to. With salaries being very low, it was unlikely that the purchase of such materials would be prioritized in their professional practice or within hospitals where they might work.

We initially brought a couple of test kits: Wechsler Intelligence Scale for Children – 4th Edition and the Wechsler Preschool and Primary Intelligence Scale – 3rd Edition and the British Picture Vocabulary Scale - version 3. These were tests I had myself or were donated by colleagues at Great Ormond Street Hospital, London. Access to these materials meant that we had more to work with rather than only our subjective observations.

Who to assess?

The multidisciplinary team is comprised of nurses, child psychiatrists, occupational therapists, psychologists, and psychiatric clinical officers, many who have completed an advanced diploma in child mental health. These colleagues are the backbone of child and adolescent mental health care in Uganda. It was key to engage colleagues to refer into the clinic and identify who might benefit from the assessment.

Before establishing a weekly clinic, I discussed cognitive assessment with the team, how it can be helpful and who might benefit from it. My multidisciplinary colleagues were interested and excited by the prospect of having the clinic and seemed to understand well how it could be utilized. Within two weeks, we had 8 referrals. These referrals comprised mainly of children with epilepsy, intellectual disability, attention deficit hyperactivity disorder, brain tumour and autism. There may have been children with other conditions but these will have been undetected due to lack of service provision (little input from paediatricians, paediatric neurologists or neuroradiological investigation). The only test we had access to was a 20 minute electroencephalogram which the families had to pay for and therefore some could not afford, so went without.

Getting more materials

I was invited to deliver workshops on cognitive assessment by a colleague, Dr Roscoe Kasujja, at Makerere University, Kampala who leads the MSc in Clinical Psychology. However, I needed materials to run the workshops.

I have been a long time member of the excellent US-based PED-NPSY list serve, and so invited members on the list serve to donate unused tests. More than twenty colleagues donated eighty tests and inventories. The materials covered the full range of neuropsychological domains: language, motor skills, social cognition, visual perception, intellectual function, academic attainment, memory and executive function. I felt so lucky to be a part of a supportive community.

Colleagues sent queries about how I planned to ensure that the materials would be used appropriately, not breach copyright laws and how we would manage the cultural constraints of using the material in a country which has had very limited experience of neuropsychological evaluation. Other colleagues offered advice based on their experience of using similar tests with minority, often disenfranchised, non-English speaking groups in their own countries (North America, UK and Ireland). We did our best to consider these factors in the clinic, which I will describe below.

Training Workshops

There is no professional training on neuropsychology in Uganda so the next step was to guide trainee clinical psychologists to use the assessment materials. We scheduled five days of workshops. The trainees were invited to review and prepare two tests in pairs. The trainees worked hard and excelled at the role play, presentations and zeal with which they approached the materials. It was helpful to have input from 25 Ugandans on how appropriate or relevant aspects of the material were and how the context could impact on interpretation of findings. We had long discussions around scoring, READING THE MANUAL, interpretation and feedback. I found the trainees and colleagues to be thoughtful and creative.



Figure 2. Getting going with the Bayley Scales of Infant and Toddler Development (Photo credit: Kirstie Fleetwood)



Figure 3. Role play with the Wechsler Preschool and Primary Scale of Intelligence™ - Third Edit (Photo credit. Kirstie Fleetwood)



Figure 4. Investigating the Peabody Receptive Language Test (Photo credit. Kirstie Fleetwood)



Figure 5. Don't forget the adult measures: Wechsler Adult Intelligence Scale – 3rd Edition (Photo credit. Kirstie Fleetwood)

Cognitive assessment clinics

Once we had completed several workshops, we started to schedule clinics. The cognitive assessment clinical was weekly and filled up quickly. The usual model of preparing and reading the manual, observing a colleague (me or another trainee who had already been trained) and

then administering the test with close supervision was used. Following which we scored up the materials and the trainees drafted a report. This was an interesting experience as direct feedback seems less common in Uganda than other countries and the trainees had to adjust to the information and me jumping to salvage a query or correction on a test. Another cultural learning point was valid culturally specific responses to questions such as “Why is it important to eat vegetables?”. The answer which many children gave of “It makes your blood flow well”, although not a correct response on the British validated test, is a fact that is taught in primary school in Uganda so needed to be accepted with full credit.

We saw many interesting cases. Many children had global challenges and the focus was showing these needs and making a case for understanding and help. For other youngsters we saw more varied profiles and in these cases we could recommend and sometimes implement specific interventions with memory, processing speed and attention.

The clinics were not without frustrations. Some trainees neglected to draft reports in a timely manner, usually due to low confidence or an 'African time' approach to completing tasks. However, we all learnt something from the communications and the families received their reports in reasonable time.

Report writing

We drew up a simple report template which encompassed the usual headings of background, concerns, behavioural observations during testing, results (in this case very broad strengths and weaknesses with no standard scores), formulation and recommendations. We limited length to two pages. We included only qualitative descriptions of the test results and used concrete examples to demonstrate the cognitive domains tests given that none of the material was validated in Ugandan. The emphasis was consistently on the recommendations section, which is culturally where the emphasis was rather than on diagnostics. Our role was to maximise benefits of both diagnostics and intervention.

Feedback sessions

Feedback to the family following a detailed assessment is one of my favourite aspects of the assessment process. This was a highly varied experience. In general, Ugandan people love to talk. There is a lot of chat around everyday experiences and for the most part I have noticed that the language is highly skewed to focus on the positive. An example of this is that if you ask someone how they are, even if they are very unwell, they will respond to tell you that they are 'somewhat fair'. Unfortunately, this cultural bias made it quite difficult at times to help a family recognise a child's cognitive impairment. Our message that although the child could learn and progress they were likely to do so far more slowly than their peers and perhaps never achieve the academic accolades that their family aspire to. This was difficult for many to hear.

We had teachers attend several of the feedback sessions. Questions asked often related to aetiology of the difficulties that the child experienced, and their future prospects. This was similar to my experience of discussions with families in the UK. The main difference related to the limited provision of specialist support for the child within school, which was clearly a concern for teachers and parents alike.

Doubts and next steps

The experience has been thought provoking, enriching and fun. I have been left with some uncertainties, which is healthy when working cross-culturally in clinical neuropsychology. I wonder what difference possession of tests and training will make to the psychologists in the long-term. Part of me is concerned that the tests will sit in the cupboard gathering dust. I am also hopeful that this experience will provide inspiration for the Ugandan psychologists to see the benefits and validity of including neuropsychological assessment and formulation in their professional lives. In February 2019 I received an update from Ms Rebecca Akello, trainee psychologist at Butabika. She wrote "The clinic is going really well. We are always testing, writing reports and doing feedback. We do less psychotherapy but it's nice and we have learnt a lot to help the children. I think we are going to be busy as we have lots of referrals."

Part 2: Feedback from trainees developing expertise in Neuropsychology in Uganda

Bachayaya Akello Pauline, and Nangonzi Josephine

School of Psychology, Makerere University, P.O. Box 7062, Kampala, Uganda

We are currently trainee clinical psychologists at Makerere University, Kampala, Uganda on placement at Butabika Hospital. We work with children and adolescents at the Children's Ward. We have also received a wide range of training in the area of cognitive testing, as a result, interest in working with children has grown hugely. We both share the hope to pursue a career in mental health of children and adolescents.

Developing expertise in Neuropsychology

The opportunity was offered to any trainee interested in learning about cognitive testing and so we joined. Each having only ever seen one cognitive test - the WISC-4, and administered it once!

At the start, we did not have many tests. When the tests arrived, we were informed right away and encouraged to get familiar with them, look at each kit and see what might interest each trainee to review and present at the workshops.

Our initial experiences of testing were interesting, with much focus on "not messing up", and trying to get the instructions right. Exposure to tests and administering them is a great opportunity and one we shall always be grateful for.

Each step in the training process was practical. First was looking at the materials of each test going to be administered, becoming familiar with the tools. This was followed by reading the manual, understanding and getting instructions right. There was always time to consult Tara about the nuances in testing that may not have been clear. We had administration training workshops, were given time to prepare and present the different tests with short role plays. Training also included sessions about giving feedback. Our responsibilities were designed based on our training needs. Appointments were scheduled followed by administering tests. Preparation was essential as it provided technical support to trainees and helped them move towards offering skilled assessment. There was emphasis on the need to develop a good working relationship with the child and communicate effectively with different stakeholders; parents, teachers and referrers. There had not been much in this an aspect of our course practice up until this point.

The Assessment Clinic

When a clear process was in place to follow, work in the clinic was uncomplicated. New clients were referred; their history reviewed and we considered whether it would be beneficial for them to undergo assessment, bearing in mind the ethics of doing so. This was drummed into us

from the very beginning. Not just any one is assessed, only individuals thought to need understanding of their cognitive strengths and weaknesses.

Information was obtained through observation, accounts of performance/behavior by the family and specific concerns that might arise. While developing the clinic, we have been encouraged to regularly consult with and learn from colleagues, in addition to seeking up to-date published information as a guide for using and developing 'best practice'. Continual interface is needed to understand the child's presentation and developments in research.

Trainees looked at the formulation, including the results and make recommendations for the child. Personally, it was highlighted that evidence-based practice is important in the delivery of our work as psychologists. Learning about different disorders such as intellectual disability, dyslexia and profiles in autism was also helpful.

Giving Feedback

Feedback sessions were initially scheduled for a month after assessment. However after handling several cases, Tara felt we were able to deliver reports much earlier and that set a precedent of having the sessions a week after. Gradually this trend has picked up.

Through these sessions, it was clear how important it is to always communicate information clearly and concisely both in writing and verbally. The template created for the report at the ward was easier to use, than any other used before. Most importantly it suits the stakeholders here because it is direct, and easy to comprehend.

We have learnt that being positive and sharing relevant pointers is effective. However in this practice, it is good not to inflate the truth, especially for clients who may not have positive results. The outcome of this process is give appropriate suggestions and recommendations for positive actions for the client.

The opportunity of working effectively as part of a team with fellow trainees was edifying. This included being able to lead, facilitate and assist during assessment. Professional growth is necessary for work we do.

The impact of our role is not difficult to demonstrate, because there has been a positive response to the clinic. It is such a joy to see families whose children have declined in functionality: socially, occupationally (with school work, which is the leading complaint), finally with clarity and understanding of what plagues their children. It is wonderful to know these tests can help the family and mostly children and adults who need them. And indeed, following a feedback session of one client, we were invited to make a short presentation (about the child's condition) at their school, first to the senior management then to the overall school staff.

There were some are limitations observed during the process. The cultural context for administration, that is to say, some items included in these cognitive tests are not germane to the Ugandan context. Sometimes it was not possible to ask the question without distorting the meaning. From time to time, this led to difficulty in interpreting performance and scores. Aligned with this was the difficulty with language barrier, whereby a few examinees are not

versed with English. Translation would at times make the process lengthy and less reliable. For some words, when translated they change the meaning which would cause a discrepancy.

Butabika is the only mental health referral hospital in Uganda. This presents some complexity especially when complex cases are referred. There can be overwhelming numbers rationed amongst few staff, with even less material resources needed for the growing population being cared for. Professionals to use cognitive assessments are few compared to the number of patients with needs.

Without a doubt, more training is needed for the examiners to acquire the necessary skills. Being able to understand and explain the works and importance of these cognitive tests all require a supervisory hand. It is key to note that for one to acquire the requisite skills in a field, in this case cognitive testing, one must have the test, and even be a certified psychologist. This presents a question about ethics. How will expertise be acquired without the vital supervision of a trained person to pass on the knowledge?

Opportunities

The opportunity to work with experienced professionals was unexpected but welcome. In case it was not clear, the training was free! There was no charge to any of us or our colleagues. The work environment Tara created was open, any one was free to express their uncertainties but mostly to flourish in their abilities.

Cognitive testing services are quite expensive. However we need to appreciate that Butabika hospital is offering these services for free which gives a chance to the parents who cannot afford the expenses.

For the future clinical work, one research concern or question is should we have studies to develop and validate tests here in Uganda and Africa as a continent. The main focus would be to adapt tests without changing the meaning or purpose of the tests but being able to fit into African culture and populations.

Psychology is still developing in Uganda. Its impact is slowly growing. Feedback sessions have shown that cognitive testing is playing an important role in children's lives. What is evident, is there need for neuropsychology in health rehabilitation.

For us, the opportunity to work with an expert in the field of neuropsychology is one we appreciate. Without a doubt, it is invaluable to the aspirations we hold for our future career. Sure it is volunteer work, but a privilege nonetheless working with such a knowledgeable, patient and in a title we consider esteemed "Teacher", someone who instructs and helps you grow. It is rare and we shall treasure it!

The Authors

Tara Murphy, Consultant Paediatric Neuropsychologist, tara@thegrowingbrain.com

Bachayaya Akello Pauline, Trainee Clinical Psychologist, klo.arch@yahoo.com

Nangonzi Josephine, Trainee Clinical Psychologist, nangonzi.jose@gmail.com

References

Bangirana P., Seggane-Musisi, P.A., Giordani, B., John, C.C., Opoka O.R.,

Byarugaba, J., Ehnvall, A. and Boivin, M.J. (2009) A preliminary examination of the construct validity of the KABC-II in Ugandan children with a history of cerebral malaria. *Afr Health Sci*; Sep;9(3):186-92.

Chernoff M.C., Laughton B., Ratswana M., Familiar I., Fairlie L., VhemboT., Kamthunzi P., Kabugho E., Joyce C., Zimmer B., Ariansen, J.L., Jean-Philippe, P. and Boivin M. (2018). Validity of Neuropsychological Testing in Young African Children Affected by HIV. *J Pediatr Infect Dis*. Sep;13(3):185-201.

Duggan, M. (2010). Epilepsy in rural Ugandan children: seizure pattern, age of onset and associated findings. *African health sciences*, 10(3), 218-25.

Molodynski, A., Cusack, C., & Nixon, J. (2017). Mental healthcare in Uganda. Desperate challenges but real opportunities. *BJPsych. International*, 14(4), 98-100.

Kaddumukasa, Kaddumukasa, Kaddumukasa, M.N. Buwembo, W. Munabi, I.G. Blixen, C. Lhatoo, S. Sewankambo, N. Katabira, E. and Sajatovic M. (2018). Epilepsy misconceptions and stigma reduction interventions in sub-Saharan Africa, a systematic review. *Epilepsy & Behavior*, 85, 21 - 27