

Providing Spine Care in Uganda,
"Gakyali Mabaga," there is plenty of work ahead!
Isador H Lieberman MD MBA FRCSC
May 2012

As a kid, Mark Kayanja, MD, PhD, aspired to someday make a difference in his country of Uganda. By virtue of his families status he received a better than average education and went on to become an orthopaedic surgeon at the Mulago Hospital in Kampala. After ten years of service in the sparsest of medical conditions, Mark realized the limitations of all his efforts. In 2000, Mark showed up on my doorstep, willing to work for free as a spinal research fellow. As impressed as I was by his offer I was more intrigued by what brought this brilliant young man to my doorstep. After four years of working directly with Mark, listening to his stories about the lack of spine care in Uganda, I had succumbed to his encouragement to accompany him on a visit to Uganda. In retrospect I now realize Mark had this all planned the day he met me.

Our first Spine Surgery mission was preceded by much anxiety and anticipation. I was deeply concerned about the conditions and wanted to ensure that we not leave disasters in our wake. After having done the first ward round it became obvious that we could improve the plight of many of these patients (see figure 1). The care of spinal trauma, osteomyelitis/discitis and spinal deformity were all far below contemporary North American standards and even basic standards. A second potentially limiting concern was the availability of spine surgery equipment and funding. Thankfully, I have found over eight years of missions that many are truly generous with their support and that the major medical device companies were willing to provide us with all the supplies to essentially handle any spine surgery reconstruction, anteriorly or posteriorly, from the base of the skull to the tip of the coccyx. The effort to generate support for these activities is year around and takes a commitment similar to that needed to get through medical school.



Figure 1; the spine ward at Mulago Hospital

Spinal pathology in Uganda is relentless, and health care provision is inconsistent at best. The system is plagued by many different constraints than what we experience in North America, yet much of the time the outcome is surprisingly similar. For example, trying to obtain a CT scan in a timely fashion; In Uganda the patients can't afford to pay for it, in North America the insurance companies frequently deny coverage, the ultimate result is that if someone does not take responsibility treatment is delayed or denied.

The hospitals in Uganda are as much of a cottage hospital system as you can imagine. The facilities are typically cramped and in disrepair. In contrast the operating theatres were surprisingly clean, however the equipment was aged and lacking in maintenance and repair. There are no reliable intra-operative portable or c-arm x-ray facilities. The OR lights typically do not function, the backup portable OR lights are weak and there is a shortage of surgical linens, sheets and gowns. Along with the preceding the lack of water and electricity renders the sterilization of equipment predictably un-predictable. In addition much to my chagrin, I found that the hospitals recycle everything including the suction tubing, the cautery hand pieces and even the surgical sponges.

With each trip I remain troubled as I realize that what we take for granted or consider disposable in our high tech, high cost health care environment, is absolutely priceless in Uganda. The simplest things like tape, gauze bandages, sterile dressings, OR linens are all considered a limited resource and potentially re-usable by the Ugandan health care professionals.

The Ugandan health care professionals are compassionate, caring and for the most part a dedicated group. What is lacking is education, experience and a basic infrastructure, i.e. appropriate trauma triage, adequate ward conditions, appropriate equipment maintenance, etc. At this stage of the development of their health care infrastructure, the acquisition of new modern and more costly equipment would be counterproductive. What is absolutely essential is a concerted effort in education and training of all tiers of the health care delivery team.

One of the most disturbing circumstances I had witnessed over 8 mission trips to Uganda was the lack of expertise in the maintenance or repair of equipment. Some of this is due to economic issues, where they are simply unable to afford the manpower, and some was just lack of training. As an example, at one hospital a well meaning donation of a CT scanner has been sitting idle in a shed, still unassembled for the past 10 years. Apparently one piece of hardware or software is missing, no one seems to know what, and the administration cannot afford to get the manufacturer to send the expertise to sort out the problem. The result is a well meaning, yet wasted effort. Other examples exist of ward equipment, operating room equipment and even fluoroscopic units, that which with just minimal maintenance could be very functional.

The people of Uganda are remarkable. In deference to North Americans the Ugandans have absolutely no sense of entitlement and do not seem to adhere or foster any form of dependant behavior. They are amazingly appreciative of anything you can do. Even something as simple as acknowledgement of their predicament is graciously received and respectfully accepted. I found the people and patients to be spectacularly resilient to social and physical stressors, ably adapting to overcome any obstacles. There is never a question of how to adapt or why to adapt. Most of the patients we examined had succumbed to one of three spine related etiologies: trauma from falls and motor vehicle accidents, infections (especially Pott's Disease/TB of the Spine, see figure 2), and congenital deformities. However, in between all of the ordered chaos, treatment discussion, and documentation, not one of us could ignore or deny the plight and suffering that unfolded around us.



Figure 2; the team examining a 12 year old girl with Pott's TB.

The misfortune of patient A.F. was all but impossible to disregard. Akelu, as she was lovingly called by her grandfather, was a nine year old girl with a mangled body, who ostensibly had seen far too much pain in her short life. Due to the extent of her deformities and the malignant volume of anomalous bone growth that progressively disfigured her, her case was deemed inoperable. This was crushing to her and her family especially considering the arduous journey from a distant village just to lose all hope (See Figure 3).



Figure 3- Patient A.F, 9 year old female with Myositis Ossificans Progressiva

Even with unfathomably discouraging moments came other encounters that quickly reminded the team and myself of the immense opportunity for us to improve the lives of others. One of our former patients (S.L) arrived unannounced at the Katalemwa clinic during a recent mission. We had operated on him in 2006 to repair injuries sustained in a devastating industrial accident. After being paralyzed and bed ridden for months with a spine fracture, the surgery allowed him to walk into the clinic of his own accord. He appeared in great shape and was so thankful to the team for restoring much of his function (See Figure 4).



Figure 4; Patient S.L., 2 year follow up, stable spine, able to walk, Lt to Rt Lieberman, Patient S.L., Kayanja

After the first trip I began questioning myself and the purpose of the Spine Surgery mission. Are we really making a difference? Are we premature in our efforts? Are we causing more harm? Are we upsetting the balance? Are we introducing false hopes? On the day of our departure when we saw the beneficial results of our surgical intervention it became clear that we can make a difference. A woman with TB moved her legs for the first time in 4 months. A gentleman with a broken neck sat propped up in bed for the first time in 5 months. A child with a congenital spondyloptosis had a tremendous deformity correction and relief of pain. I still however really struggle with the age old ethical dilemma; who do you pick? The pathology is overwhelming, the need insurmountable, and one must come to realize that we will never be able to take care of everyone.

As each mission ends I reflect on the lessons learned; 1) trust your instincts, 2) always biopsy, 3) infection rarely skips levels, 4) be versatile, innovative and adaptable, and 5) just how much you can do in the dark, without suction or cautery, and with a good, sharp Cobb elevator.

Without any reservations I encourage everyone to participate in a charitable mission in one way or another. It will change your life. To those who are considering participation in a medical mission I offer the following advice. Know the local facilities and have a local host. They will steer you away from trouble and support all your efforts. Engage and involve a multi-disciplinary team. Ideally the team should consist of a surgeon, scrub nurse, anesthetist, equipment technician/ engineer, x-ray technician, recovery room nurse and a physical therapist. Each one brings a different expertise and will compliment the skills of the next. And finally once on site do not forget about involving and teaching the local health care professionals. At first there will be some skepticism, but over time the bond and trust will develop and they will then impress you with their gains in knowledge.

On one hand, for myself and I am certain for those who accompany me, providing spine care in Uganda is most gratifying. On the other hand, leaving so many patients uncared for is troubling. Today, after eight mission trips to Uganda, having provided spine care to well over 400 patients, and establishing lifelong relationships with colleagues and students, I am deeply indebted to my friend and colleague Mark Kayanja, who by virtue of getting me involved in Uganda, has re-affirmed in my mind why I am a physician.