Measuring disability due to lymphoedema in rural Ethiopia

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I am very grateful to the BAD for supporting my research visit to Addis Ababa University in Ethiopia. This was a great chance to meet with the team of researchers led by Professor Abebaw Fekadu, in the Centre for Innovative Drug Development and Therapeutic Trials for Africa (CDT-Africa).

During this short visit, I experienced first hand some of the challenges of undertaking research in developing countries.

The initial plan was to spend a few days collecting field data, in Amhara state in Northern Ethiopia with the local research team. My intention was to use existing disability tools (SALSA scale and Participation scale) to assess the impact lymphoedema has on patients.
However the location of the research site was not far from Bahir Dar, which at the time of my arrival was the site of a coup attempt which resulted in the killing of several people including Amhara state president and Ethiopia's army Chief of Staff. I was told it was not safe for me to continue to Bahir Dar, and I remained in Addis Ababa.

On Monday I met with Prof. Fekadu, a few of the post-doctoral researchers, and various other members of the team. I had a tour of the department and Addis Ababa University (AAU).

On Tuesday, I was hopeful that things might have settled giving me the chance to travel to the research site. There had been no internet across Ethiopia for the last few days and phone signal was unreliable. I was informed that guns were still being fired in Bahir Dar, which seemed like a good enough reason to stay put in Addis Ababa. That afternoon I had a very useful meeting with Dr Kassahun Habtamu, Assistant Professor in the school of psychology at AAU. He had experience of measuring disability, specifically in adapting the WHODAS questionnaire, to make it relevant for menta health in Ethiopia. He had lots of good advice on how we might go about adapting and validating a tool such as the Participation scale to meet our needs.

Wednesday and Thursday weres spent at All Africa Leprosy, Tuberculosis and Rehabilitation Training (ALERT) hospital in Addis Ababa. I saw many patients with leprosy, including new cases of lepromatous leprosy, patients of all ages with severe physical deformity (many of the older patients treated during the era of dapsone monotherapy), and cases of both type 1 and 2 leprosy reactions. I joined the leishmaniasis ward round, covering two wards full of patients with cutaneous leishmaniasis, who were admitted for treatment.

On the last day, I spent the morning at San Giuseppe lymphoedema clinic, a non-governmental organisation that recruits patients from churches all over Ethiopia. The majority of the patients attending this clinic had podoconiosis, although some had leprosy and a few possibly lymphatic filariasis. Group sessions with 30 or more patients were run by nurses; they involved teaching patients the key aspects of lymphoedema self-care, including washing of the affected limbs, application of emollients, massage, simple exercises and in some cases compression bandaging. An obervation is that these sessions also functioned as self-help groups, giving patients the opportunity to talk amongst themselves, share their experiences and laugh.