A real life drama in a neurolathyrhic family.

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After witnessing the appalling nature of the recent neurolathyrism epidemic that occurred in northeastern Ethiopia I was compelled to write to a local newspaper. Frustrated by the slow pace of measures taken to deal with the epidemic, if any, the prime objective of my narrative script in the newspaper was to raise public awareness towards the disease by sharing some basic facts (2). Following are excerpts from the script:

"Not too far in the course of time, in remote northern Ethiopia, after cruising over beautiful but arid highlands and valleys for about 6 hours on a mule back, under a scorching sun, I was in a native thatched hut.

In that rural family I saw both the patriarch and the matriarch of the household including their two daughters and two sons. They were taking their usual morning sunbathe just in front of the verandah of their hut concomitantly also clearing their underwear off the unfriendly lice and bugs. Recognising the arrival of my group, the family attempted to offer the traditional respect by bowing but unfortunately to no avail. All but one girl were crawlers.

They were recent victims of the crippling disease of lathyrisim what we call in Amharic Ye guaya Beshita. The family totally depends on neighbours and relatives for its living. The patriarch tearfully told me he was praying for his death just to 'escape' the agony of watching the suffering of the family. This family is just one amongst the thousands...."

This was my true experience that had happened in October 1997 in Delanta Dawint district of North Wello, one of the 8 districts that were afflicted by the epidemic. From the script one can rightly guess that I was moved by pity for that family. Then the epidemic was still going on. The regional state health bureau called me from the district where I was working to confirm the “alleged” neurolathyrism epidemic as I had a previous research experience on the disease. I led a team of health professionals that investigated the epidemic. As part of our investigation we visited sampled families to examine patients who had recently developed the disease. It was at this juncture that I caught the glimpse of this family. The terrible situation of the family is still vivid in my memory. Then, my physical examination of all the crippled family members confirmed that they had the most severe stage of the disease. They had to crawl even to move a single metre’s distance. All the classical upper motor neuron disorder signs and symptoms were present. The adductor stiffness and the muscle weakness were severe. And most of all, their psychological integrity was indeed in an appalling state.

The area has persistently been afflicted by recurrent drought. It was the airing of the grim pictures of the famine around this area (Wello) by the BBC TV journalist Jonathan Dimbleby that caused a public riot that led to the demise of the monarchy of Ethiopia in 1974. During my visit in 1997 grass pea was the only surviving crop after a drought caused by shortage of rain and it had been consumed in its different forms: boiled, roasted, bread, unripe green seeds and gravy. The consumption of the pulse in the form of the fermented unleavened traditional pancake (injera) was reported for the first time from Ethiopia in this area (3)

I also remember quite clearly that a panicking health worker in the nearby clinic was at a loss in dealing with the increasing number of neurolathyrism cases. He was consistently advising the community “to avoid contact with the steam of the grass pea foods and the drained off water of the grass pea” echoing the prominent misconceptions that prevailed in the area and elsewhere in Ethiopia. He was not aware that grass pea contains a toxin, let alone knowledge of home based detoxifying methods.

Soon after the confirmation of the epidemic- amongst the many recommendations and activities - a surveillance system was established in the district to monitor new cases. Prompt supply of relief services and aggressive neurolathyrism information, education and communication (IEC) to the health workers and the community were also recommended. However, to date, no single pamphlet or brochure about neurolathyrism has ever been produced. Another important recommendation of ours was to seize the moment for further biochemical and epidemiological study of the disease. Most of the previous biochemical and epidemiological studies on the disease have been carried out on “old cases” that had been crippled for more than 10 years at the time of the studies (4,5). The established surveillance system revealed that the epidemic continued until 1999 and 8 districts were afflicted from North and South Wello administrative zones. There were also reports of pockets of increased cases in a neurolathyrism endemic in north-western parts of the country during the period (5).

However, the impetus for this contribution to the newsletter is my May 2001 visit to the district and the family I mentioned on that newspaper article. The ordeal of reaching the district was somewhat similar to 1997 except that now more makeshift roads were constructed through food-for-work schemes allowing
my experienced and enduring driver to cruise with his four-wheel drive vehicle more areas than during my previous trip. The food-for-work scheme is a way of encouraging relief dependent communities to be engaged on terracing and makeshift road construction activities so as “to combat dependency sentiments”. These makeshift roads had helped a lot in curtailing the distances to be traveled off the road either by mule back or on foot as compared to 1997.

When I visited the family in May 2001, I was able to see the father, the mother and one of their daughters (Plate 1). One of the neurolathyritic sons and the healthy daughter had left for a bigger city to solicit income for the family through begging. The family had not heard from them for more than 6 months. The other son is now living with his healthy and childless aunt in another village.

Interestingly on my recent visit to the family the victims were no longer crawlers. Both the mother and the father showed some improvement and they are now using two sticks to walk. This is a shift from Stage IV of the disease to Stage III according to Acton’s disability grade (1). This time, unlike 1997, the mother can now perform basic household chores to feed the family. Now, there was no need for her to be tied with a rope to the wall of the hut in order to prevent her from falling down while grinding grain with traditional tools. Physical examination revealed that there was much improvement in adductor stiffness and muscle power, particularly in the mother and the father. However, the young daughter, although she managed to stand up using two sticks—which is an improvement compared to 1997—has more adductor stiffness and shortening of the Achilles’ tendon. Although not examined, similar improvements were described for the absent, previously paralysed children of the family. The parents disclosed that this improvement happened after a few months following the arrival of relief food and decreased consumption of the grass pea.

This simple observation has led me to conduct non-structured in-depth interviews with selected patients of all stages of the disability. It was found that victims who already have developed the disease feel a worsening of the clinical condition when they consume grass pea foods. Particularly those unmixed food types—the raw unripe seeds (eshet), the roasted (kollo) and the boiled (nifiro) forms were incriminated as causing more adductor stiffness and locked knee, worsening of gait, heaviness in the legs and marked “tingling backache”. One stage II patient who had eaten the boiled form of the seed the night before the day of the interview dramatized the worsening of his clinical condition. He explained that in order to walk now he has to exert more force on his sticks and his toes are rubbing more with the ground than the previous day. It was further disclosed that cold exposure augments these effects and much worsens the clinical presentation of the patients. The interview with all the patients elucidated that the worsened clinical conditions was said to “normalize” once the victims cease consumption of grass pea foods—which often is very difficult to them in the absence of other foods.

Ludolph et al reported that some patients might experience partly reversible symptoms suggestive of a diffuse CNS excitation of somatic, motor or autonomic function (7). However, these observations might suggest that current grass pea dietary habit could alter the clinical presentation of established cases. It is very difficult to draw any conclusion from these observations as one can rightly argue that these changes could also be attributable to the natural rehabilitative and adaptive efforts of the patients. However, I believe, it is high time to closely look at the different intertwining factors involved while studying the medical aspect of neurolathyrysm-not only the neurological or the clinical features. Epidemiological risk factors, nutritional and environmental factors that alter the course or the presentation of the disease are cases in point to be further scrutinized.

From the tragic condition in real life of this crippled family could emanate information contributing to the understanding of the etiology of this neurodegeneration as was the case for the tragic experience at the Vapniarca concentration camp (6). Although, traditional qualitative methods (such as the in-depth interview) are not much applauded in medical research for the abundance of information of a subjective nature, there is a recent movement advocating their crucial role in the understanding of disease realities (8). I believe integrating qualitative methods in neurolathyrysm research would contribute to our understanding of the complete etiology and picture of the disease and for its prevention and eventual elimination.

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References

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Plate 1. Members of a family affected by neurolathyrisim in Ethiopia.