

Title: Impact of genetic education on services and community perceptions

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What problem was addressed: Medical genetics has become the cornerstone of modern medicine. Unfortunately, African patients don't have access to medical advances offered by genetics. Mystical beliefs about the origin of diseases are widely prevalent in many African countries resulting in inaccurate and potentially harmful perceptions on the origin of diseases. This leads to delays in diagnosis, treatment regimen, timely referrals, and management of genetic diseases. There is a gap in most physicians' knowledge and skills to recognize genetic diseases and provide appropriate treatment. A recent paper shows that lack of genetic knowledge is the major cause of delayed diagnostic and treatment in DR Congo (Lumaka and al., 2016). The need is to update the medical curriculum with genetic courses and training to improve physician ability to recognize and manage diseases with genetic component.

What was tried: Our project was to update the medical curriculum and raise awareness of genetic diseases in the community. We conducted a series of faculty development seminars and secured the support of the dean, the genetic team, and other stakeholders. Our project has been accepted as part of the operational plan of our faculty for the coming five years and a task-force has been given the responsibility of developing an action plan to update the medical curriculum. This has provided us the opportunity to advocate for the formal introduction of a genetic course and to develop curriculum.

We also organized multiple meetings with parents of children with intellectual disability. A social network composed of parents and patients' associations for genetic diseases including intellectual disability, Down syndrome, and congenital malformations has been built. This is a useful channel to convey our message to the broad community, change perceptions of disease origin so that children are diagnosed and treated early in the disease progression.

What lesson was learned: Change doesn't come until we advocate and act. Institutional advocacy and action through faculty seminars have led to the preparation of a course offering in genetics as part of the medical curriculum. A cadre of physicians will be prepared who will have knowledge and skills to diagnose and manage genetic diseases.

There is a need to engage multiple stakeholders for advocacy, project planning, as well as implementation. Besides the support of professional stakeholders such as institutional leaders and peers, we also included community members as stakeholders. Our interactions with parents revealed that they were in desperate need of information and knowledge regarding the afflictions of their children. They had questions and wanted to get answers but did not know where to go and who to talk to. When we conducted our meetings in the community, explaining the origin of diseases, they understood better the problems of their relatives and engage better with the medical systems approaches to disease management.

Reference:

Lumaka A, Lukoo R and al. (2016) Williams-Beuren syndrome: pitfalls for diagnosis in limited resources setting. Clin Case Rep. 4(3):294-7.