Observations as a doctor in a TB hospital

To the Editor: Something that struck me when working in a TB hospital was the marked difference between the enthusiasm of patients to get their ARV treatment compared with that for TB. I was intrigued by the fact that some patients queued to get one set of pills and defaulted on the other.

TB has been around for a long time and is so to speak passé. It was not always so. Literature and Art glamourised the consumptive. As improved living conditions led to the virtual disappearance of the disease, so TB became forgotten in Europe. This is still largely so, despite the massive resurgence that we see now.

HIV on the other hand is a relatively new disease with much attention from the media. Indeed, there are parallels with TB, where TV stars, sportsmen and pop singers with HIV/AIDS are now the ones being glamourised. The successes of ARV treatment have been widely publicised, despite the fact that they have been available to but a few. Many people in poorer circumstances still die from the disease.

The process associated with being started on ARVs is unique. There are elaborate and clear guidelines for those who will be selected to receive the potentially life saving drugs. The diagnosis of the disease, the choice whether to keep the diagnosis hidden from others, the intense counseling process and the need to fulfill certain non-medical criteria before treatment is started, make it exceptional. It is extraordinary to have only “good” patients offered treatment.

Exclusiveness with all its ambivalence is a characteristic of HIV. This ranges from stigma, taboo and exclusion from society to individual counseling, support and hand selection of patients. There seems to be a strong connectedness in the ward amongst the people who are on ARV treatment. There is a clear group building process and strong support for each other - a situation that will most likely change when the same patients are discharged to their homes. In contrast, I never observed any connecting and group building of the “normal” TB patients. (MDR patients might be slightly different).

It seems as if TB could be seen as the older unattractive rather dull sister of HIV. Money and manpower is put into research into HIV and ARVs; the South African HIV Clinicians Society has got its own rather fine colourful journal, which is easily available. TB journals are expensive, drab and scarce: While HIV flowers, TB seems to wither.

Nurses gave their associations with these two diseases: TB was connected with a grey or pale colour. It was described as tasteless. It evoked tired bored feelings, images of rubbish bins and run down unreliable cars. Mended again and again they would die on the owner sooner or later. One nurse said that TB resembled a slug, leaving slime all over the place. Another portrayed it as a ghost, or a spider web: if one moved ones hand one could not grab it but still feel its existence. Ignorance about Tuberculosis seemed to be related to the lack of interest this everyday disease evoked, and to the boredom it caused. HIV in contrast was seen as being bright red or black. It had a sharp or very bitter taste. HIV was like a tiger or a snake that waits for the right moment and then bites and poisons the victim. One nurse described HIV as a fast glossy car of good quality that lasted forever. Ignorance about HIV apparently derived from fear and anxieties of death.

Clearly these associations are not meant to be representative. The metaphors that are connected with different diseases however will influence their perception and treatment success.

Adherence to medical treatment seems to differ remarkably between TB and HIV. The success rates in ARV adherence appear to be linked to the unique counseling and selection process as well as to the fact that it is still a “young” treatment, which is connected with light and hope in a deadly disease. TB does not evoke these hopes any longer. I would be very interested to find out from my patients whether they connect TB with death as strongly as they do HIV. I have the impression that - against all facts and reality - patients fear to die of HIV quickly but believe that their lives are not threatened by TB. (The XDR-outbreak is possibly now changing the picture). They feel that TB treatment can be taken arbitrarily, whereas ARVs need to be given now and regularly.

Integration of TB and HIV treatment is vital as these two epidemics fuel each other. The successful approach to HIV/ARV treatment is a model for any other chronic disease. But there might be more to it than the patient’s good training and treatment supervision. How one impresses effectively on people the need to take TB and its treatment seriously is a matter for further discussion.

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