

PROJECT PORTRAIT

Conflicted cure: Default & adherence in DR-TB treatment #01 (2013)

What is this project about?

This is an anthropology study that looked at drug resistant tuberculosis (DR-TB) patients in Khayelitsha and their adherence to the treatment. The topic arose out of TB work of MSF (Doctors without Borders) and was suggested by patients involved in an earlier study.

The research focused on how history, the environment and personal characteristics affect the default or adherence to the treatment offered for DR-TB. This study looked at the accountability of both the individual patients and the governmental bodies responsible for treatment.

The research

The research focused on the journey of DR-TB patients through their treatment. In order to do this

the researcher developed a relationship with some patients and shared their lives for more than three months. The research followed the lives of these patients and observed their attitudes towards the illness and treatment.

What did the researcher do?

The researcher attended support-group sessions where she met all of her research participants. She used a participation-observation method called witnessing. She also conducted illness-narrative interviews with the participants and interviewed five nurses. The participants were grouped according to their gender, and focus-group discussions were held with each group. A research assistant from Khayelitsha was hired to assist with some of the fieldwork. All the verbal and written materials were translated and transcribed.



Daily doses of treatment with difficult side-effects



What you need to know :

More people need to be educated about DR-TB in order to reduce the number of those defaulting on their treatment. The language used to describe the adherence of the patient to the treatment puts all the fault of non-adherence on the patient. However, this study shows that failure and neglect within the health system are part of what causes an individual patient to 'default' from such a difficult treatment.

The research findings

This study found that a number of factors affect defaulting on treatment, rather than an individual patient failing to keep to his/her treatment schedule. DR-TB and its treatment are equally understood as a death sentence to the patients. Patients often experiment with their treatment. They split their pills in half or stop taking treatment for short periods to reduce the side effects they suffer.

The study found that patients were punished by the nurses for speaking out and not sticking to a strict routine with treatments. These patients were made to wait long for assistance.

Strict adherence to the treatment requires for the patient to default on some other aspect of his/her life. The counselling and group sessions came second to treatment thus making it difficult for the patients to fully unpack their feeling about the

treatment and its effects on their lives.

While there is no easy or clear solution to patient treatment adherence, there must be a sensitive and imaginative dialogue that can look at these challenges in ways that will bring more dignity to those both giving and receiving care.

Using the research

This research may be used to develop educational materials for people suffering from DR-TB. One of the reasons patients default unknowingly is through not knowing the purposes of the drugs in securing their good health.

Future research should look at the relationships between DR-TB patients and the nursing staff that administer their treatment.

This study was completed in **February 2013**.

Want to know more?

Research was carried out by Laura Winterton in the Department of Social Anthropology, University of Cape Town. This summary is based on her Master's thesis "Conflicted Cure: Exploring Concepts of Default & Adherence in Drug Resistant Tuberculosis Patients in Khayelitsha". The project was supervised by Dr Helen Macdonald and Dr Fiona Ross. The thesis is available via the Co-op website.

Keywords: drug resistant tuberculosis; treatment; default; adherence; nurses.

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