



School of African & Gender Studies, Anthropology & Linguistics

Anthropology Section

Arts Block, University Avenue, Upper Campus
Private Bag, Rondebosch 7701, Cape Town, South Africa
Tel: +27 (0) 21 650 3678 Fax: +27 (0) 21 6502307
Internet: www.uct.ac.za

**DEFAULT AND ADHERENCE IN DRUG RESISTANT TUBERCULOSIS PATIENTS
IN KHAYELITSHA**

FINAL REPORT

RE: LAURA WINTERTON'S RESEARCH FINDINGS 2012-2013



UCT KNOWLEDGE CO-OP

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Laura Winterton
winterton.laura@gmail.com
+44 078 332 18537

INTRODUCTION

This report presents a summary of findings from qualitative ethnographic research conducted on ideas of 'default' and 'adherence' among DR-TB patients seeking treatment in Khayelitsha, Cape Town. The goal of the research was to further understandings and discussions about the well-known factors (i.e. substance abuse, depression, employment and physical side effects) that affect a patient's ability to complete their treatment regimen. Many of the aforementioned challenges emerged both explicitly and implicitly throughout the research, however, the data from three-and-a-half months of field research demonstrate layers of psychosocial issues, that are lesser known or under researched, physical side effects that manifest themselves into anxieties about the future are present in patients' everyday treatment seeking behaviours. Findings suggest that 'default' and 'adherence' are absorbed in complex logics and multiple understandings of treatment and side effects that are often not shared by biomedical and public health practitioners. The data revealed that the concept of a DR-TB cure is a 'conflicted' process since the treatment was understood to degenerate the very object it was meant to cure, (the body, the self (mind) and a confidence in the future). The psychosomatic side effects of the treatment are embedded in a range of factors from language, perceptions of the self (gender identity), relationships with health workers, education, relationships with the medication, stigma, employment opportunities, suicide and moving between different systems of care (prison to community clinics). These anxieties manifest themselves in very tangible ways, either through 'experimentation' with medication as a way to manage or control side effects or suicidal inclinations (death as escape from suffering or unburdening family and friends).

EXECUTIVE SUMMARY

The data for this research was collaboration between the researcher (Laura Winterton) and the research informants (DR-TB patients) and MSF. This research is based on three-and-a-half-months of fieldwork that employed ethnographic research methods to capture data. The data was procured through eighteen illness history interviews, five in-depth case studies, which utilised creative methodologies that were designed in collaboration with research participants. Participant observation was conducted five to six days per week for five to eight hours per day in patients' homes, clinic, church services and shopping centres. The researcher also attended two weekly DR-TB support group sessions facilitated by MSF. Lastly, the researcher coordinated four gendered focus group discussions. * Please read the data collection section for further detail on the methodologies.

- The relationship between the nursing staff and patients has a profound effect on patients' treatment seeking behaviours. Patients have reported to abscond from their treatment because of the way they are treated/spoken to in clinics.
- Five patients said that they they felt that they could not disclose the intimate details about their experiences with treatment with their doctor, support group staff either due to time constraints or fear that their complaint might not be taken seriously, or be brushed off as "common side effect".
- Nurses felt that they are not equipped to deal with DR-TB patients, as there is a lack of training and professional development related to DR-TB treatment.
- Nurses felt they should receive more financial compensation or further incentives when working with DR-TB patients due to the level of risk they assume in their jobs.
- Patients claim to know about TB but are unaware of DR-TB until they are diagnosed with it. Therefore, more public awareness is needed about DR-TB in the community.
- Patients did not understand, yet expressed a desire to learn about the details of their treatment i.e. names of medication, specific side effects and the length of side effects.
- Six patients "tailored" their medication to militate against the negative side effects.
- Ten patients became forgetful, incoherent and absent minded from the medication and feared walking home after taking their medication at the clinic because their state of mind made them vulnerable.
- Men complained of impotence and expressed a great deal of anxiety about their masculinity and the future of their romantic relationships.
- Women spoke about irregular or terminated menses, which produced profound concern about future fertility and their sense of femininity.
- Both men and women complained about the changes in their physical appearances, they reported that their pigmentation changed, developed rashes, boils and pimples all over their bodies consequently

making them feel “ugly” and “unfamiliar” to themselves. There was a sense of alienation from their bodies.

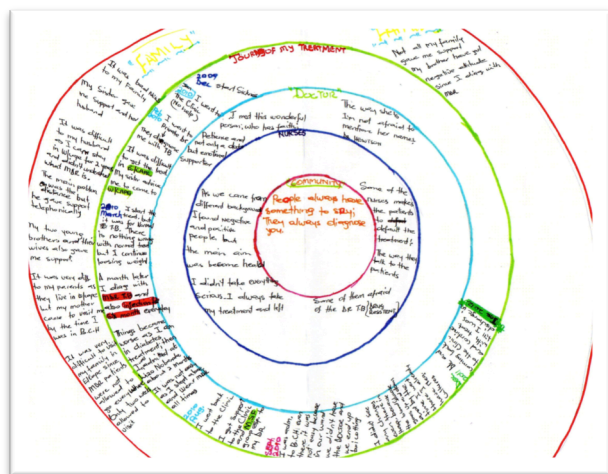
DATA COLLECTION METHODS

This research drew on a variety of qualitative methods, emotional maps, semi-structured interviews, participant observation, language survey, collage, family trees and focus groups. The researcher accompanied patients in their daily routines both within the clinic space as well as their homes. The researcher attended two weekly DR-TB support group sessions (Matthew Goniwe and Site B). Eighteen illness history interviews were conducted with patients from the support group sessions.

COLLAGE



The collage was created with empty pills packets from a female patient’s weekend treatments. It demonstrates her relationship with her ‘toxic’ self. She mapped her emotional reactions to the medication, her fears and anxieties, and the moments when she was surprised by the help that the treatment offered. It was a way for her to visually trace the emotional and physical side effects that presented themselves throughout treatment.



EMOTIONAL MAPS

This process gave patients the opportunity to think of their treatment through certain categories – they divided their maps into relationships: “nurses and healthcare workers;” “family;” and “community”. Patients reflected upon the ways in which these relationships helped or hindered their ability to remain ‘adherent’ to treatment. Working through these stories as a visual chronology triggered certain memories or experiences that did not surface during conversations and interviews.

FAMILY TREES

A family tree cannot be given as an example in order to protect anonymity of both patients and their families. However, the purpose of the family tree was to explore avenues of emotional and financial support/neglect from kin, community and other patients.

FOCUS GROUP DISCUSSIONS

The researcher administered four focus group discussions with DR-TB patients who attended MSF’s weekly support group sessions. The sessions were divided between male and female participants in order to assess what distinct challenges patients encountered that were directly or indirectly related to their gender.

LANGUAGE SURVEY

A language survey was distributed to some DR-TB patients to evaluate patients' reactions to the language used by medical staff on default and adherence. It was a useful exercise to gauge how patients interpret and react to biomedical categories and explanations.

FINDINGS

RELATIONSHIPS

- Eight support group sessions, five interviews and many informal conversations revealed that nurses punished patients for perceived infractions to their treatment regimens: arriving late for an appointment, complaining about a member of staff, criticising a nurse for the way that s/he delivered the injection. Punishments took the form of making patients wait for a long time before administering their medication.
- Patients believe that nurses didn't care or lacked compassion. There were frequent complaints from patients that the nursing staff verbally abused them or were unnecessarily aggressive when giving injections.
- Three nurses stated that they "lacked compassion" for patients who they believed would "offend" or "re-offend" (this language referred to defaulting patients).
- Three nurses said they were not given the support they needed from their superiors and were overworked with tasks unrelated to treating patients (i.e. cleaning and answering phones).
- Tick sheets were not always properly managed so patients were marked as absent when they were in fact present. Often, nurses would fill in the tick sheet at the end of the week rather than on a daily basis. In turn this influenced nurses to label patients as absconders or defaulters. One patient discontinued treatment during the research period because of this very issue.
- Support group members routinely complained that nurses could not answer specific questions about the particularities of DR-TB medication.
- Five patients said that their complaints about the more emotional or psychological side effects of the medication were not taken seriously by both doctors or nurses i.e. they were laughed at, ignored or told that the side effects were 'normal'.
- Language of nurses and doctors felt incriminating and demoralizing for some patients, making them feel like "less than human." Patients heard sentences like the following "you must want to die" or "you must like being on treatment." Patients understood that the language that staff used was a way to influence 'adherent' behaviour, which worked for some patients but not on others. For some it has the opposite effect as it was felt to be patronizing and abusive.
- Patients complain that counseling sessions are too brief and feel secondary to the management of drug regimen. Patients therefore do not initiate discussion on issues that may require more time or emotional sensitivity.
- Patients are afraid to voice their opinion when they they are confused or do not understand the treatment regimen because they feel overwhelmed by the diagnosis and the details about treatment.
- Not all patients can produce sputum when required. Consequently patients feel they should to discontinue taking treatment until they can produce a sputum sample, that is, patients feel like they are "volunteering" for treatment. Many patients tell one another that they are "volunteering" and that "there is no point in taking treatment" until they have results from the sputum sample.
- The family tree revealed that the majority of a patient's grant money goes to support their family and friends both in Khayelitsha and the Eastern Cape.
- With regard to the emotional support the family tree gave evidence that many families cannot offer emotional support to a DR-TB patient, therefore, reiterating that a "treatment buddy" system cannot rely on a family member or even close friends to offer the support that a patient requires throughout the course of his or her treatment.
- Family members felt overburdened by the demands of caring for a DR-TB patient.
- Three patients who were interviewed said that they did not inform their families of their diagnosis because they were concerned that they would be evicted from their homes or made to give their grant money to support the household.

SUICIDE

- Many patients had never heard of MDR or XDR-TB prior to diagnosis, so they equated the diagnosis with a death sentence.
- Patients contemplated suicide (most notably at the beginning of their treatment, because they did not believe that DR-TB could be cured).
- The side effects of the medication make many patients “lose their minds”, “forgetful”, “angry” and as a result they believe that it would be easier to end their suffering.
- Patients who raised suicide in support group sessions were often chastised. These utterances brought a lot of stress and anxiety to the other patients and peer educators, who saw suicide as a sign of “giving up.” Those who raised the issue of suicide were often silence in the support group session. It is not clear from the support group how suicide is perceived and managed.

“TAILORED TREATMENT”

- Patients often split their pills in half to experiment with and reduce the negative side effects.
- Some patients “pause” their treatment on weekends in order to enjoy a day with food, or time with friends and family without the immediate side effects that come with ingesting the medication.
- Patients often attempt to wait until they get home before taking their pills because they get “spacey” or “forgetful” when walking home and fear that they are visibly vulnerable to others in the community (i.e. fears of being robbed, knocked over by a car or losing your way home). This means that patients are able to negotiate when they take their treatment with some nurses or they discreetly bring their pills home with them.
- Patients have strong negative reactions to the smell, taste and/or colour of the medication. Some equate the colour of certain pills with death and would prefer to avoid them. Three patients told me that they associate the colour green with death.
- Lack of communication contributes to the tensions between patients and nursing staff. For example, on one occasion a brand of a medication changed and patients were suspicious and anxious. They felt there would be additional side effects, that the new drug wasn’t as good, or they would have to start their treatment from the beginning with the new medication. The nurses did not take the time to explain the change in medication, possibly because they didn’t know why and they didn’t have the time. A MSF counselor addressed the issue. Another example: Patients were given pediatric medication because of an interruption in pill supplies – nobody was available to clarify this change. A patient complained about the confusion and as a result some of when, the following day, the DR-TB patients were made to wait the entire day before they were given their medication (possibly the result of confusion regarding the medication), the lack of explanation made patients assume that they were being punished.
- Patients said that in the hospital they were getting Ofloxacin and in the community based care (through MSF) they were getting Moxifloxacin. Patients believe that MSF has access to better drugs and they are deeply anxious about what will/would happen to their treatment once the government takes over delivering DR-TB care in Khayelitsha.
- Patients expressed an interest in getting more education about the actual pills. They want to be able to refer to them by their names rather than their colour or shape. They think charts that detail the drug regimens should be displayed in the clinic.

GENDER IDENTITY (SENSE OF SELF)

Men

- Men no longer felt in control of their sexuality, they were no longer sexually aroused. They complained of impotence. They could no longer engage in sexual relations with their partners adding another layer of stress into their home lives.
- Men often spoke of uncontrollable anger or frustration that frequently surfaced due to the loss of sexual desire and the shifting dynamics this produced in their intimate relationships.

- Male patients suggested the implementation of couples support group sessions so that they can speak of issues related to sexuality in front of their partners with the support of other men around and the confirmation that it is happening to others.
- They complained that their physical appearance changed (became “ugly”). As a result of the medication they developed rashes, boils and blisters over their bodies. Shame over their ‘ugliness’ resulted in few people addressing this issue in support groups.
- Many men started to drink alcohol or more heavily whilst on treatment as a coping strategy or to “forget” their stress.
- Many of the men who were interviewed previously worked as petrol attendants, general labourers, stocking freezers and refrigerators and they expressed a fear that the lasting effects of DR-TB would not allow them to continue with the that form of employment in the future.
- Three taxi drivers associated their TB infection with their work and fear re-infection should they return to this type of employment. They felt at a loss as to their employment opportunities after they completed treatment.

Women

- Some women expressed feeling estranged from their bodies as they were no longer able to recognise themselves in front of the mirror (changes in complexion, loss of weight, rashes, boils and pimples).
- Women felt anxious about their menstrual cycles (some stopped menstruating while others had longer and more painful menses). This was particularly challenging for young women who desire to have more children yet believed infertility to be a permanent side effect of the medication.
- Signs of premature aging: women complained of joint pain to the extreme that they move like “90 year-old women” and feared that they would never have the robust body they had prior to treatment. They were also plagued and frustrated by unreliable memory and train of thought. Five women said they lost their train of thought in midsentence, forgot what people were asking them, had difficulties keeping up with conversation or forgot entire conversations the following day.
- Some were concerned about the quality of life once treatment is complete (i.e. will they remain weak and stiff?).
- Several women became reclusive and moody with family and friends, inevitably making it more difficult to receive the support they needed.
- Women’s relationships with their children changed, and in some cases quite dramatically. Some left the rural areas to come to Cape Town for treatment (therefore apart from their children for the two years of treatment). Some were unable to tell their children about their illness because of shame, fear that their children would be afraid of them, or they didn’t want to appear vulnerable in front of their children.
- Four women held the belief that it is easier to live with HIV than to be cured of DR-TB.
- Many women felt that the focus on “cure” by physicians and nurses prevented the possibilities for conversations that might address different forms of coping strategies for the psychological or emotional problems that come with treatment and infection. For example, depression, suicidal tendencies, family trauma, employment, masculinity and femininity, forgetfulness and anger.

DISCUSSION

The above themes highlight the psychological, emotional and physical side effects that patients encounter when undergoing treatment for DR-TB. The identification of the characteristics and particularities of some challenges can help to inform strategies for targeted counselling techniques. Delivering healthcare in a resource poor setting is replete with challenges. Doctors and nurses are overworked which effects their interactions with patients as they have limited time and resources to spend with each patient. These findings are by no means presented as a way to diminish the efforts and work of the healthcare providers, but to begin a critical dialogue to develop strategies that can assist in delivering quality and sensitive care to patients.

While substance abuse featured in this research as a trigger for ‘defaulting’ behaviour it was often spoken of as a consequence of treatment, three men said that they drank more as a coping strategy to their treatment, or that they were bored being at home. Anxiety about what happens after cure was a profound issue for many patients. After such intense treatment for a prolonged time, patients cannot imagine a future beyond the cure. In addition, the concept of ‘cure’ is replete with anxieties about pre-mature aging, infertility, virility (masculinity),

physical appearances and cognitive impairments. A more comprehensive counselling programme would benefit patients and their families.

The relationship that patients have with their medication is intimate and complex. Personal or cultural associations with shape, colour and smell of medication have a profound impact on a patient's capacity to ingest medication on a daily basis. Patients were asked how they would re-imagine their treatment and many patients would like a liquid form rather than pills, neutral colours (white or cream) and flavoured. Although, this data is beyond the scope of policy and interventions it is a starting point for advocacy for future pharmaceutical developments and ingenuity that could take these points into consideration.

Patients expressed a need and interest for better education on the pills that they are taking. The sentiment that patients, through their experiences, are more knowledgeable than the doctors and nurses on DR-TB treatment must not be overlooked. Greater education and resources about the treatment itself will create more knowledgeable patients who will be able to speak more confidently about treatment and cure and would serve as more informed peer educators and counsellors if they are chosen.

RECOMMENDATIONS

- The primary focus for intervention should be centered on more robust and sustained counselling offered by trained professionals (some of the peer educators are not capable of coping or addressing some of the more profound issues, and many patients see them as peers so may not bring forward their most intimate concerns).
- Male/Female support group sessions (every other week or once a month there should be women's and men's only groups).
- Patients believe that a doctor or doctor-patient liaison should attend a support group once a month to learn of some of the concerns of the patients either related to their treatment (pills) or their experiences in the hospital. Some informants said that they think that they should be able to ask questions anonymously to avoid fear of retribution.
- Conduct support group sessions that directly address concerns patients have for their futures beyond treatment (employment opportunities, re-infection, pre-mature aging, infertility etc.)
- A nurse suggested that more training on language would equip them with readied vocabulary to deal with 'non-compliant' patients or patients who do not understand the treatment regimen.
- More specific education about the pill and their side effects. Some simple strategies would be to place more posters and information sheets throughout clinics.
- More public awareness about DR-TB through radio and TB advertisements. Drug-susceptible TB patients should also be informed about the strains of DR-TB. Many patients who had TB were never told about the potential DR-TB.
- Further research on the relationships that DR-TB patients have with nursing staff as they see each other on a daily basis for DOTS.
- Further research on the relationship between substance abuse and treatment or the various coping strategies that patients develop throughout the course of their treatment regimen.
- A more in-depth study on patients perceptions of the pills' taste, colour and smell could be a beneficial study to conduct with a research group in biochemistry institutes. The development of drugs that taste, look and smell differently but remain as efficacious could have great impact on patient adherence.