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Surveillance or support: The experience of direct observation during tuberculosis treatment

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Abstract

Directly observed therapy (DOT) is a cornerstone of tuberculosis control. DOT has been criticized as paternalistic, but it has also been argued that the interaction with health workers can be a source of support for patients. We explored the experience of patients in antituberculosis treatment, with the aim of understanding the balance between surveillance and support from the recipient's point of view. We interviewed 27 patients in Tijuana, Mexico, employing narrative analysis to understand how participants made sense of their illness and their experience of DOT. We found a core narrative of biographic disruption and self-reconstruction, in which health care workers helped participants to attribute a less negative meaning to tuberculosis. Interviewees accepted DOT's as necessary for other people to avoid treatment abandonment, but felt that in their case it was unnecessary. Only a few felt that DOT represented mistrust on the part of the health workers. We conclude that DOT can be a source of support when it is enacted in a patient-centered way. We discuss whether participants' lack of criticism of DOT is a case of adaptive preference, in the context of a power differential between patient and health system.

Keywords

Directly observed therapy; personal autonomy; social support; tuberculosis; health services

Introduction

In 1994, the World Health Organization (WHO) established Directly Observed Therapy Short-Course (DOTS) (World Health Organization, 1994) as the recommended strategy for tuberculosis (TB) control. Both this strategy and its successor, Stop TB, are based on political commitment, enhanced diagnostic capabilities and availability of medications, evaluation and monitoring, and other components aimed at facilitating access to treatment (World Health Organization, 1994, World Health Organization (WHO), 2006). Directly observed therapy (DOT), one of the elements of the DOTS strategy, consists of a health worker, health promoter or other trained member of the community, watching the patient every time the antituberculosis drugs are taken. With DOT, treatment control rests upon the person making the observation, a tactic aimed to improve treatment adherence (World Health Organization, 1994, 2006).

“One might [...] wonder why any adult would need to be *watched* in order to properly take the medicine that they need to save their lives and protect those around them.” The commonsense of this remark by Paul Draus (2001, p. 191) illustrates the strangeness of a practice that has, nevertheless, become of central importance to tuberculosis control programs all over the world. While direct observation of the patient was from the beginning only one among the many components of DOTS, it somehow “overshadowed” other elements (Harper, 2010, p. 203), even in the absence of clear evidence of its efficacy (Volmink & Garner, 2007). Direct observation was subject to discussion since it was first implemented, when the exigency that patients were watched over during medication intake was considered ‘gratuitously annoying’, ‘inconvenient’ (Annas, 1993, p. 587), and an intrusion upon autonomy (Bayer & Dupuis, 1995). Other authors underscored the power differential between patients and the health system, whereby the latter justifies the harm to autonomy by the public health good achieved, without taking the patient’s circumstances into consideration (Porter & Ogden, 1997). Inasmuch as it is enacted without consideration to the patient’s will, DOT constitutes a paternalistic measure. Paternalistic public health actions are justified by appealing to the ‘harm principle’, that is, the intervention is acceptable when conducted in order to prevent harm to self or community (Bayer & Dupuis, 1995). In the case of tuberculosis the assumption is that, the treatment being long and difficult, without close supervision patients would probably interrupt it, bringing harm to themselves (by non-cure and relapse), but especially to others if they become sources of transmission of drug-resistant strains (Frieden & Sbarbaro, 2007). Recourse to the harm principle in the case of DOT, however, is implicitly based on the assumption that lack of adherence is volitional, and thus surveillance of the individual is a good way to address it. This leaves on the side the social, economic and political factors that limit a patient’s ability to adhere (Annas, 1993; Farmer, 1999; Hurtig, Porter, & Ogden, 1999). Many studies have shown that those less likely to complete antituberculosis treatment are the ones in more vulnerable social positions: the less educated, the poorer, and in general those with less

access to resources (Draus, 2001; Greene, 2004; Kurbatova et al., 2012; Lewis & Newell, 2009). As ‘ought implies can’ (Porter & Ogden, 1997, p. 123), rather than focusing on supervision of drug intake, public health actions should aim to facilitate the conditions for adherence, thus expanding instead of restraining individual autonomy (Buchanan, 2008; World Health Organization, 2010).

In the original formulation, DOT was described as someone ‘accountable to the health system’ (World Health Organization, 1994) taking responsibility for treatment, with the seemingly implication that the patient is not able to function as a responsible agent for his own treatment (Volmink & Garner, 2007). In the new century, the strategy has shifted to a patient-centered approach that considers the importance of patient and community empowerment and human rights (Harper, 2010). The 2006 Stop TB strategy proposed that the supervision of medication intake ‘... should be provided by a treatment partner or treatment supporter who is acceptable to the patient and is trained and supervised by health services’ (World Health Organization, 2006, p. 10), and the more recent Stop TB global plan does not even mention the issue of direct observation (Stop TB Partnership, 2015).

While direct observation has become less important in the programmatic discourse of international agencies, it is still implemented and reinforced in national tuberculosis programs (Sagbakken, Bjune, & Frich, 2012; Mette Sagbakken, Jan C Frich, Gunnar A Bjune, & John DH Porter, 2013; Secretaría de Salud (SSA), 2013). The theoretical discussion of direct observation from an ethical point of view is extensive, and there are also many studies documenting the patients’ experiences of practical difficulties when DOT is implemented in a rigid manner (Draus, 2001; Greene, 2004; Kurbatova et al., 2012; Rocha et al., 2011). Still, relatively few studies have addressed the specific experience of being watched, and its meaning from the patients’ point of view. In this article we focus in this aspect of the experience of antituberculosis treatment, exploring if participants experienced the aspects of surveillance reported by other authors.

On the other hand, it has also been suggested that DOT can be a source of social support during treatment. Social support can increase adherence to long-term therapies, by helping patients to deal with the difficulties associated with illness and treatment (J. C. Macq, Theobald, Dick, & Dembele, 2003; Muñoz & Bertolozzi, 2009; Munro et al., 2007; World Health Organization, 2003). Health care workers (HWs) in charge of DOT can provide informational support, answering patients’ questions and easing doubts about the disease, treatment, and side effects (Mafigiri, McGrath, & Whalen, 2011; Terra & Bertolozzi, 2008), and they can also provide emotional support (Chalco et al., 2006; George, 2008).

Given the importance of DOT for TB control, this is a topic that deserves to be explored in greater depth, and in a variety of social and cultural contexts. The objective of this study was to explore the experience of DOT in individuals undergoing TB treatment, focusing on the perceived effects of this practice upon autonomy, and also on its aspects of social support.

Methods

From February to August 2012, we conducted a qualitative study in Tijuana, Mexico, a city with a population of 1.5 million inhabitants at the Mexico-United States border. Baja California, the state where Tijuana is located, has one the highest incidences of TB in Mexico, with 44.1 cases of pulmonary TB per 100,000 in 2014, as compared to 13.6 per 100,000 for the whole country in the same year (Dirección General de Epidemiología (DGE), 2015). In 2007, there were 650 cases of pulmonary TB registered in Tijuana (Brodine et al., n/d). In Mexico, the treatment of TB follows a national regulation (Secretaría de Salud (SSA), 2013), and is mainly delivered by public health care institutions. In compliance with the regulation, the treatment of all TB patients should be by DOT, for six months in the case of primary treatment, and longer in cases of retreatment or drug resistance. Because of health services overload, however, sometimes patients are seen by HWs weekly or less often, and given their medications to take home. This situation is usually limited to patients considered to be low-risk for treatment abandonment. Furthermore, during the study period a feasibility study on the use of mobile phones for remote DOT through video was being conducted at the study site. The video-DOT was intended to provide patients with a less burdensome treatment alternative, and facilitating direct observation in a resource-limited setting (Garfein et al., 2015). This allowed us to interview patients in a gradient of three DOT ‘intensities’, from traditional DOT where HWs watched the taking of medicine, to remote video-DOT, to patients who went without DOT for different periods of time.

Participants

We interviewed adult (> 17 years) patients who had completed at least two months of TB treatment at the time of interview. In order to recruit patients, HWs in the tuberculosis control program asked all eligible persons, if they would be willing to participate, and if so, would they consent to sharing their contact information with the research team. HWs gave the research team the contact information of the patients who accepted, and the research team contacted them via telephone to make an appointment for an interview. We interviewed all subsequent patients that were referred to us and accepted to participate, till theoretical saturation was reached.

Following the criterion of maximum variability (Hudelson, 1994), we interviewed patients in three types of treatment: DOT, video-DOT, and intermittent or no DOT. Patients in the first group were observed by HWs during ingestion of each medication dose. The second group received their medications at home on a weekly basis, and recorded ingestion on a mobile phone; immediately after the intake, the patients would send the video to a control center where a supervisor would revise it, carrying out a remote DOT. Patients in the third group had spent some periods or the whole treatment in self-supervision, having periodic appointments at the clinic during which they were given the medication to take home.

Interview and analysis

We conducted semi-structured interviews, following an interview guide with four dimensions: description of first symptoms, diagnosis and treatment; experience of the

disease; experience of DOT; experience of autonomy and social support in the context of TB treatment. Interviewers introduced each subject, and allowed the conversation to flow from there, exploring new aspects as suggested by the interviewees. The interviewers started by asking the patient to recount the first symptoms of TB, how he had come to seek care, and a description of diagnosis and treatment. In order to obtain information on the experience of DOT, if at this point the informant had not specifically described it the interviewers asked questions such as ‘Does anyone observe you when you take your medication?’ or ‘How do you feel when the nurse watches while you take the medication?’ Knowing that it could be difficult for patients to express negative feelings about healthcare, after asking the neutral questions above the interviewers were instructed to recognize and reflect back those feelings, so the interviewee could feel at ease expressing them.

Interviews were conducted at the patients’ homes or in clinics, and lasted 24–53 minutes (average 30 minutes). Two of the authors (IB and IS) and a research assistant conducted the interviews separately. The interviews were conducted in Spanish, audio-recorded and transcribed verbatim. For this article, a professional translator translated interview quotes into English. The study was reviewed and approved by the ethics committees of the University of California in San Diego and El Colegio de la Frontera Norte. Participants read and signed a letter of informed consent, and received a phone card worth \$ 100 pesos ($\approx$ U.S. \$ 8) to compensate them for their time, and \$ 50 pesos for transport in the cases where they traveled to the clinic for the interview.

We conducted a narrative analysis of the interviews. In narrative analysis, the researcher approaches texts not as straightforward representations of an objective reality, but as discursive constructions through which people make sense of the world (Murray, 2000). The analysis of illness narratives is a well-established tradition in disciplines such as sociology, psychology and public health, and it allows for the understanding of the social location of disease and the therapeutic process (Frank, 1995; Kleinman, 1988). In the analysis, we considered the social situatedness of participants (i.e., how narratives emerged in social contexts), by looking for differences in narrative patterns or elements between persons in different social positions (Stephens, 2011). Our analytic strategy followed three steps: first we read each interview and made notes about the overall story each one told, identifying the narrative plot (Kelly & Howie, 2007); second, we identified common and contrasting aspects of the plots; third, we focused on the role of DOT and health workers (HW) in each narrative, and searched for mentions to autonomy, social support and related concepts. The analysis was conducted separately by two of the authors, who then discussed results with each other, in an iterative process repeated till consensus was reached.

Results

We were provided with contact data for a total of 32 patients, of whom 27 agreed to participate. The mean age of participants was 35 years old, 17 were male and 10 female. Most patients had less than 12 years of education, and nearly one third were unemployed (Table 1). All of them were Mexican, and were in treatment in public health institutions.

The plot: biographic disruption and reconstruction

Participants' accounts followed the lines of biographic disruption and self-reconstruction frequently described in narratives of illness (Frank, 1995). Almost all participants began the plot with a period of ever-worsening symptoms, during which the narrator consulted doctors who failed to diagnose the disease. In the following quote, the narrator employs the phrase 'it didn't go away' as a refrain to show time going by without resolution (in this and the following quotes, *italics* represent emphasis added):

It started with a cough, like a cough with phlegm for like two months *and it didn't go away*. They gave me treatment, they gave me medicine like for, how is it called, throat infection, *and it didn't go away, it didn't go away*, and I thought this is not normal. (Interview 7, male, 21yrs)

Unease at symptoms and uncertainty were in some cases aggravated by public health services' refusal to provide care, as in this quote where the words 'come' and 'go' show the narrator's experience of being rejected by providers:

So I *came*, *came* and the nurse told me, eh, I told her 'You know what? We *come* because, eh, I got this problem and so', yes, yes, and she told me 'which delegation, which, where you *come* from?' And I told her 'well, from [name of delegation]'. She told me 'You have to *go* there'. But it was like, I felt awful, I mean, I thought, 'ouch, same as always'. It had been '*go* there, you have to *go there*', and then 'no, you have to *go* back'. So I was just like, ok [in mocking tone]. (Interview 1, female, 25yrs)

A turning point occurred when diagnosis was finally made, usually in the context of a disease crisis, such as spitting blood and arriving at an emergency room, or thanks to a helper, either HW or acquaintance, who identified the need for a TB test:

[...] and on the third day I felt like very nauseous and got dizzy and I started coughing blood, I don't know if I was vomiting or coughing blood I don't, I can't distinguish, and eh, well, I was very scared because I couldn't, I couldn't stop coughing or... it was between nausea and cough it was. Then, eh, it was, I got scared, there was blood coming out of my nose too, the blood was like suffocating me, eh, well, I called a cousin, family, she was close to where I live and, eh, cause at that time I was living with my mother, then someone close to my mother's house, and well they came and they took me to the hospital [...] (Interview 3, female, 22yrs).

While having a clear diagnosis came as a relief, knowing that the disease was tuberculosis also made a deep impression on participants, as described by other authors (Paz & Sá, 2009). At that point, some participants considered TB a 'mortal disease', and they made a discursive parallelism between it and other stigmatized and incurable diseases:

[...] and I thought I was going to be locked up in a hospital in which, in which I was going to be surrounded by *patients like me, also with terrible diseases* and I was going to be secluded [...] (Interview 10, male, 51yrs)

Charmaz (1999) suggests a hierarchy exists in the social perception of suffering, in which those who are innocent of their own disease are assigned a higher moral status than those who are to blame for it. In our study, this moral hierarchy was evident in a narrative emphasis on guilt vs. innocence. Participants felt guilt at having contracted a transmissible disease, which could in turn be passed on to other, innocent, members of the family. At the same time, they positioned themselves as not to blame, by insisting that they didn't know where it had come from:

Yes, I felt bad, *I told myself: wherefrom did it come?* Because, because they say that, eh, there're many you can catch, well, diseases from outside, I mean, do you get what I mean? But I told myself: No, I never, *I'm always working and all that, clean and all that [...]* (Interview 17, male, 48yrs)

As has been consistently reported in studies of tuberculosis patients, most participants also described experiences of rejection by friends, family, employers or others. For some participants, going to the clinic or having the HWs coming to their homes to administer their treatment was a source of anguish, inasmuch as it made them identifiable as TB patients:

Yes, and, yes and you go to the hospital and for example, the door has [a sign saying] 'tuberculosis', other people go by and, well, 'look that one going in'. As I told you, told you, right? I mean, like a person with a contagious disease and that, that is what I... mean. But now it's not like that anymore, I go there and go in and it's normal, that's all, no shame now, you know, because it's a disease and one has to abide by it. (Interview 17, male, 48yrs)

As shown in the quote above, biographic reconstruction began with the narrator re-signifying TB as 'a disease as any other disease', a 'curable' disorder one should not be ashamed of. In this way, TB became an impersonal medical concept, a biological entity to be addressed by pharmacological means. Through this process they were able to 'reset normality' (Sanderson, Calnan, & Kumar, 2015), defining the disease as 'normal'.

As they became familiar with the causes, routes of transmission and expected course of TB, participants also gained a feeling of control, so that from being a victim of unknown forces, the narrator turned into someone who had taken things on his hands. Agency at this point was emphasized with phrases such as 'you have to do your best', and a theme of responsibility towards self and others emerged:

Interviewer: Did you ever think of abandoning treatment?

Participant: Mmm, well I because, mmm, because I had this problem that I could get anemia or something, because of that I told myself 'no, I'm going to go on with my treatment and I won't leave it'. And also because, well, not to worry my mother by quitting the treatment, by relapsing or something, and that's why I went on with my treatment.

Interviewer: So you felt like a responsibility towards your mother to continue?

Participant: Mmm, well to my mother and to myself, because well I got that disease who-knows where and I had to cure myself of it, yeah. (Interview 7, male, 21yrs)

The story's epilogue showed the participant feeling better physically, satisfied with his accomplishment, and waiting for the treatment to end and complete cure to be achieved.

The role of health care workers, and the experience of direct observation

Participants in the DOT group visited the clinic daily, and some of them had participated in a temporary program in which the HW visited their homes instead. In both cases, the HWs supervising the treatment were female. Participants in intermittent DOT visited the clinic weekly, and received their medications from female nurses or doctors. Participants in video-DOT were visited weekly by a male HW.

While we had expected diversity in terms of the degree of surveillance and support that participants in each group experienced, we found the descriptions of the relationship with HWs to be similar in all cases. Independently of contact frequency, HWs were instrumental in the change of meaning ascribed to TB, by informing participants about the medical understanding of tuberculosis, thus providing the narrator with the discursive elements to position TB as a normal and curable disease. Participants went to them for information about medications' side effects or the results of follow-up tests. For participants who had been rejected by other people when their diagnosis became known, the personal relationship with HWs was an important source of support. They were generally described as nice, professional people who were doing their job and could be trusted.

During fieldwork and initial data analysis, it came to our attention that when interviewees described going to the clinic to take their medications, and their interactions with HWs, almost none of them mentioned the actual moment of being watched over. In the interview guide, respondents were asked to describe current and prior therapy, and researchers expected DOT to be sufficiently significant for it to be mentioned spontaneously. However, in most cases it was not so. When the participant did not mention DOT in the first description of therapy, the interviewer would ask, 'Does anyone observe when you take the medicine?' by which we expected to get a description of emotions and thoughts associated with being watched over. To this question, most interviewees responded by saying simply 'yes' or 'no,' or briefly describing the act of receiving the pills and taking them, without a clear emotional tone in the response.

Only four participants, after questioning by the interviewer, mentioned discomfort at being watched over. They also described how they had come to terms with discomfort by getting to like the HWs, and also through accepting DOT as a required procedure for tuberculosis control:

Interviewer: And when the health promoter came she would gave you the treat...
eh, the pills, and you would take them in front of her?

Participant: She would arrive, open the pills, go for my glass of water, she would put them in my hand, watch me take them and she would leave.

Interviewer: And how did you feel with, with the fact that she, she was watching?

Participant: Well, at the beginning I felt like, like it was too much fuss, like... I mean... But I developed a good relationship with her as, as a partner who would bring me my medication, and at the time I just had to accept things as they were.

Interviewer: So at the beginning it was not very easy.

Participant: Well, it was, ah, not easy, well, yes, I did feel a little bit uneasy but, well, I knew it was for my own good. No problem. (Interview 8, male, 29yrs)

Interviewer: How did you feel with that [observation]?

Participant: Ah, well, it was not awkward but, how could I put it? On the one hand it's OK, they're observing that you take your medications, but on the other yes, it seems a little bit of mistrust on their part, that they don't trust you, not a little bit.

[Further on in the interview] [...] No, it's not awkward but it's that, I told you, trust is very important to me, right? But, but if, for example they don't know us, that's what happens on their side they don't know you and eh, and it's a procedure they have to do and you shouldn't feel bad about it. (Interview 13, male, 23yrs)

When asked if they knew why they were made to come to the clinic, all patients were aware that tuberculosis treatment was supposed to be supervised, and knew the reason for supervision was to prevent abandonment. They followed the regulations, while at the same time emphasizing those were in place because other people might abandon treatment, but this was not their own case:

Interviewer: Did they explain to you why the therapy was like that, taking your pills in front of them?

Participant: Yes, because they say many people has relapsed because sometimes they don't come for their medication, or take the medication home and they forget it, and don't take it, some forget and some just don't take it. But you do it for your own good, well, I do it for myself, I come at the time they tell me to come, I take the medication here. Once I told her [the nurse] 'I'm going away from the city, give it to me to go' '¡No! You have to come for them', she says, and I had to come for them. (Interview 22, female, 43yrs)

In this way, they recognized the paternalistic aspect of DOT (as a practice that existed because patients could not be trusted), but positioned themselves as not being the kind of person it applied to. This narrative work allowed participants to maintain a congruent sense of themselves as worthy moral agents (Charmaz, 1999), but the paradoxical position remained, as expressed in a scene where the participant separates herself from the position of the watched one, by making a joke about being watched over. She also emphasizes her good relationship with the HW, thus giving DOT a less imposed status and more of a sense of shared responsibility:

Interviewer: How did you feel, being watched over when you took the pills?

Participant: Well I felt that, that, that they were watching for one's good, mainly for it, right? For your own good. Because what would they care, right? It was for our good. Yes, yes, I didn't feel awkward, on the contrary, I liked it, I felt protected, I

did not, no, did not feel awkward at all [Interviewer: You didn't mind]. No, no, no. I just told her [the nurse] 'Hey, you're checking me out, right?' [laughs]. I mean I go along with them [HWs] very well now, with all of them, even with the doctor. (Interview 9, female, 35yrs)

The scene also exemplifies the convergence of support and surveillance, from the participant's point of view, in the experience of being at the same time 'protected' and 'checked out'. Other participants (notably mainly females, cfr. Sagbakken et al. (2012)) repeated this theme of DOT as an almost parental care, with disciplinary and caring tones occurring in parallel:

Interviewer: So you like being supervised?

Participant: Actually, yes. Yes, it's OK, you do feel like more pampered, like more 'You know? You have to do this'. I mean, it is not like 'You have to do this and that's it' [imitates scolding voice], but yes, who doesn't like to be told 'You know? It's for your own good'? [Imitates sweet, caring voice], (Interview 1, female, 25yrs)

In sharp contrast to the absence of spontaneous mentions to the actual observation, the narrative of most participants stressed the considerable practical difficulties that going to the clinic to receive their medications entailed. For many of them the cost of transportation was an important barrier. Also, most were self-employed at the time of diagnosis, or had a job without paid sick leave, so that not showing up for work in time because of a clinic appointment directly affected their income. DOT also conflicted with other activities and responsibilities. Participants with formal employment and social security were better off, being able to take days out of work. These patients were also perceived by HWs as trustworthy and given their medications to take home or enrolled in the video-DOT program, and tended to be in better socioeconomic position, so that the social positioning of participants was an important determinant of how much DOT interfered with their daily lives.

The patient and the health system

While the focus of this article is not on patient-health system relations as a whole, one noticeable aspect of the participants' narratives was their description of having to negotiate access to health care, as well as the conditions of treatment. In the first episode of the narrative, some participants described providers' refusal to receive them. When already in treatment, participants described being allowed to take the medications home as a privilege, which had been gained by convincing the HWs of their trustworthiness. The power differential was clear (Sagbakken et al., 2012), with participants mainly accepting that they had to comply with regulations and softening the situation with the notion that it was done for their own good.

Discussion

At the beginning of this article we introduced the criticism of DOT as a paternalistic procedure. However, other possibilities have been suggested, in which DOT, instead of a strategy of surveillance and control, turns into a patient-centered strategy with the HWs

collaborating with the patient to overcome barriers to treatment adherence (Bender, Peter, Wynn, Andrews, & Pringle, 2011; J. C. Macq et al., 2003; Paz & Sá, 2009). As other authors have found (Bender et al., 2011; Terra & Bertolozzi, 2008), frequent contact with HWs was important for our participants inasmuch as it provided them with informational and emotional support. That this can be done without the HWs having to supervise drug swallowing was evident, as patients who were or had been in self-supervision or video-DOT also mentioned the HWs as a source of support during weekly encounters. If tuberculosis control programs de-emphasize the aspect of surveillance of DOT, frequent contact with HWs could serve a different purpose: that of expanding autonomy by providing the patient with the elements to make informed decisions and act in accordance with those decisions (Buchanan, 2008). In this regard, it is not only informational and emotional support that are relevant, but many studies show that material support is essential in order to facilitate adherence to treatment (Greene, 2004; Kurbatova et al., 2012; Rocha et al., 2011; Smith-Nonini, 2005). This is the approach suggested by the Stop TB strategy, with its focus on patient-centered care and community empowerment (Stop TB Partnership, 2015). In Tijuana, projects conducted by civil society organizations and the Ministry of Health have also promoted this strategy (see for instance <http://soluciontb.org/principal>).

Sagbakken et al. (2012) describe DOT as a disciplinary practice, an act of surveillance in a Foucauldian sense, and argue that it violates the principle of using the least restrictive means to achieve the objectives of public health (Mette Sagbakken et al., 2013). In a study of immigrant patients in Norway, those authors found that most of them considered DOT humiliating and discriminatory, and only a few perceived it as a form of care (as in our case, it was mainly female patients that mentioned the latter aspect), and they report similar findings in a study in Ethiopia (M. Sagbakken, J. C. Frich, G. A. Bjune, & J. D. Porter, 2013). Similarly Hansel et al in Baltimore found that participants 'resented the implied lack of trust' (Hansel, Wu, Chang, & Diette, 2004, p. 648) of DOT. In a study in Nepal, one patient is quoted as saying that HWs "... think we're all stupid and can't be trusted" (Lewis & Newell, 2009, p. 190). All of the above coincide in documenting the patients' negative perception of DOT as a practice that places them as untrustworthy and subjects them to humiliating treatment. In contrast, only one participant in our study mentioned a similar feeling, and in a relatively mild way (see quote of Interview 13 above). In what follows, we want to suggest three interpretations for our contrasting finding.

The first is that, as Buchanan (2008, p. 17) puts it: 'Autonomous agents can adopt moral constraints, willingly submitting to norms...' From this point of view, participants willingly accepted the constraint represented by DOT, in order to get better, but also as a form of responsibility towards their families and community. While this interpretation may be partially correct, for a decision to be considered autonomous it is necessary that different options are present (Nussbaum, 2002). For participants, the only other alternative was to go without antituberculosis treatment, so that their actual range of decision was actually very restricted.

The second interpretation of the relative absence of discomfort with DOT could be that the moral experience of it was less relevant for the participants, in comparison to other aspects of their illness experience. Yang et al (Yang et al., 2007) have defined the moral experience

as ‘what is most at stake for actors in a local social world’. It is possible that, for participants, being able to keep jobs and continue fulfilling their role as family providers, resisting discrimination or simply feeling better physically, were more significant than the experience of being subjected to observation, which was therefore not even mentioned in the narratives.

A third aspect to consider is the possibility of adaptive preferences (Nussbaum, 2002), those developed by persons with restricted options to conform to the choices available. Siding with the HWs and accepting DOT as necessary, could be a case of making a virtue out of necessity by individuals used to accept health services without much questioning. From this point of view, the lack of perception of the surveillance aspects of DOT would not mean that such aspects do not exist. In this regard, it is interesting to notice that the four patients who mentioned discomfort with DOT had an education level of 10 years or more, with one of them having some college studies and another having completed college. This educational level is higher than the average for the sample, and also higher than the average for the Mexican population. A study in Mexico showed that among users of public health services, education was inversely associated with service satisfaction (Puentes Rosas, Gomez Dantes, & Garrido Latorre, 2006), which could imply that more educated people, who are likely to have more choices in general, are better positioned to voice dissatisfaction. As some HWs delivering treatment have less than college education, the power differential for these four cases could be less marked than for the other patients.

An important limitation of our study was the procedure we followed to contact potential interviewees. As we got in touch with them through the tuberculosis program, it is likely that they saw us as related to the health system and responded in consequence. The fact that one of the interviewers was introduced to potential participants as ‘the doctor’ was also important in this regard. In addition, participants were ‘success cases’, in the sense that they had adhered to treatment for at least two months by the time of the interview, so that the experience of patients who abandoned treatment before that time is not reflected here. It is possible that the experience of cure made participants more positive in their vision of treatment. However, as all participants commented freely about the difficulties that attending the clinic imposed on them, we believe that, had they experienced negative feelings directly related to DOT, they would have been able to express them. Also related to the sampling process, while HWs were supposed to ask all eligible persons if they would accept to be contacted by the research team, we can’t be sure if this was so, and we don’t know the number or characteristics of possible refusals at that point. The generally positive relationship with HWs described by participants might reflect a selection bias, in which HWs referred to us mainly patients they trusted. As with all qualitative research, another aspect to be considered is that the sample was not intended to be statistically representative, so the transferability of results should be assessed by the readers taking the context and sampling procedure into account.

Conclusion

To conclude, for participants in our sample DOT delivered through attendance to the clinic was an annoying practice, which conflicted with their everyday lives taking a toll on already

scarce resources, but for most of them the specific fact of being watched over while taking the medication didn't seem specially obtrusive. At the same time, frequent contact with receptive and caring HWs was an important source of informational and emotional support. Putting these two findings together, as others before (Bender et al., 2011; J. C. Macq et al., 2003; Paz & Sá, 2009; Sagbakken et al., 2012; World Health Organization, 2010) we suggest that the role of HW-patient interaction during antituberculosis treatment should change from surveillance to support. From the descriptions of participants in our study, it seems HWs already perform a sort of informal selection, giving those patients they consider less likely to abandon treatment some leeway to take their medications home. This, however, should not turn into a practice of disciplining only those considered untrustworthy (Sagbakken et al., 2012), who would likely be the most vulnerable. More recent approaches to antituberculosis treatment by international organizations promote a more 'patient-centered treatment' (Harper, 2010; World Health Organization, 2006, 2010) and customized approaches have been proposed taking into consideration the needs of patients and engaging them in the decision making process of treatment (Lienhardt & Ogden, 2004; Lonnroth, Tran, Thuong, Quy, & Diwan, 2001; J. Macq, Torfoss, & Getahun, 2007; J. C. Macq et al., 2003; World Health Organization, 2006). Following these lines, patient empowerment can be promoted, and public health protection achieved while maintaining the principle of using the least restrictive methods and respecting human dignity (Hurtig et al., 1999; Verma, Upshur, Rea, & Benatar, 2004).

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Table 1General characteristics of participants, by treatment group^{*}

	TOTAL (n=27)	Directly observed therapy (n=10)	Video-observed therapy (n=8)	Intermittent directly observed therapy (n=9)
Age (range)	19–69	21–69	19–29	20–67
Male	17	7	4	6
Female	10	3	4	3
Marital status				
Single	10	4	3	3
Married/common law	13	4	5	4
Separated/divorced	4	2	0	2
Years of education				
0–8	12	5	3	4
9–11	10	4	2	4
12	2	0	1	1
12+	3	1	2	0
Occupation				
Housewife	7	2	3	2
Non-skilled	7	0	2	5
Professional	3	0	2	1
Informal	2	2	0	0
Unemployed	8	6	1	1

^{*} See definitions of each group in Methods