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ORIGINAL ARTICLE

Disconnecting the DOTS: misconceptions about the therapeutic paradigm of tuberculosis patients at family healthcare centers in Istanbul

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Abstract
Purpose There has been a major transformation in the Turkish healthcare system since 2003. The new paradigm introduced the family medicine model, which profoundly changed the structure of primary healthcare access and delivery. In the context of tuberculosis (TB) control, it led to transferring the responsibility for directly observed therapy (DOT) from anti-TB clinics to family healthcare centers. This change entailed daily interaction of the health staff of family healthcare centers with TB patients who had been treated solely in anti-TB clinics under the vertical system since the 1940s. These encounters resulted in erroneous DOT practices and inappropriate treatment of TB patients. In this study, we attempt to question the ways in which TB control has so far been and will possibly be affected by this change.
Methods We collected our data through semi-structured, in-depth interviews with ten family physicians, ten nurses/midwives and ten TB experts in Istanbul between January and December 2012.
Results Our interviews revealed that family physicians predominantly think that they are not well equipped to deal with TB patients in terms of infrastructure and time. Besides, it seems that most of them have misconceptions about DOT and the transmission route of TB.
Conclusion Our research points out that the aim and rationale of DOT should be clarified for the healthcare staff of family healthcare centers. We also assume that if an inappropriate approach toward TB patients in primary healthcare settings prevails, this will negatively affect the help-seeking behavior of TB patients and hence the treatment success in the long run.

Keywords Tuberculosis · Turkey · Family medicine

Introduction

Tuberculosis (TB) was at the forefront of the public health agenda for decades in terms of morbidity and mortality. Although the incidence, prevalence and mortality rates have been decreasing[1] significantly for decades, intensified immigration to Turkey, the constant increase of multidrug forms and culmination of one third of all active cases in Istanbul makes TB a public health priority.

Turkey has a long history of success in the fight against tuberculosis (Aksu and Toprak 2012; Yildirim and Gurgan

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[1] The incidence and prevalence rates were 58/100,000 and 51/100,000, respectively, whereas it dropped to 28/100,000 for the former and 24/100,000 for the latter in 2010. The mortality rate decreased from 7 per 100,000 in 1990 to 3 per 100,000 in 2010 (Yildirim et al. 2013).

2012; Gokce 1968). The most significant milestone in this process was when the National Tuberculosis Control Program adopted the Directly Observed Treatment Strategy-Short Course (DOTS) in the second half of 2006 (Yasin 2007). The DOTS program aims to control TB by breaking the chain of transmission through the rapid detection, identification and cure of infectious cases (WHO 1997; WHO 1999; Davies 2003). By doing so, the goal is to reduce the morbidity and mortality worldwide (Porter et al. 2002). The adoption of DOTS in 2006 is of particular concern to the present work, because after this date directly observed treatment (DOT) was supposed to be implemented in all dispensaries throughout the country. DOT is an essential component of DOTS, which intends to ensure TB patients take all their medications. The 'observer' is often a healthcare worker, and he/she observes the patient taking every dose of his/her medication during treatment and keeps records in the health system for monitoring (Frieden and Sbarabo 2007). While the countrywide implementation of DOT was only 50.9 % in the second half of 2006, it gradually increased and reached 98 % in 2010 (Yildirim et al. 2013).

Of course, the transition to DOTS cannot be examined independently from the effect and outcomes of the "Health Transformation Program," which is a neoliberal reform package that has been implemented in Turkey since 2003 (Yasar 2011; Yilmaz 2013). The reforms encompassed a range of policy areas in terms of both service provision and financing of the healthcare services and brought about a dramatic change in the structure of primary healthcare. Dictated and monitored by the World Bank, the major thrusts of the reform package were the integration of separate security schemes under the Social Security Institute, development of a state-private sector partnership for hospital management and implementation of a family medicine model within a performance-based framework (Ocek et al. 2014).

The introduction of "family medicine" as the new locus of primary healthcare services in the country altered the basic framework of the organization of the primary healthcare services (Kisa and Kisa 2006; Ocek et al. 2014). The district-oriented model that has prevailed since 1961, aiming at integrated primary healthcare and public health services based on a population-based structure, has been replaced by a model based on the separation of these two functions. Family healthcare centers sought to provide patient-specific preventive and diagnostic, curative, rehabilitative and counseling services at the primary healthcare level, whereas community health centers maintained basic public health services at the community level. Family physicians (FPs) who are mostly general practitioners work at family healthcare centers to provide primary healthcare for the people on their lists. Midwives, nurses or emergency medicine technicians are regarded as a single unit under the name of Family Healthcare Workers to work with FPs (Ocek et al. 2014). The countrywide transformation was not completed until the integration of family practice in Istanbul in 2010, one of the last major cities to embrace the program. Istanbul is the largest metropolitan city in Turkey with an estimated 13 million inhabitants (Cakir et al. 2014). It is also outstandingly significant in terms of the TB burden (TC Saglik Bakanligi 2014), putting enormous pressure on the National Tuberculosis Program.

The new system has not only changed the health environment dramatically, but also had implications for the National Tuberculosis Program. One such implication was the transfer of the responsibility for DOT from anti-TB clinics (from now on I will refer to them as "dispensaries") to family healthcare centers. In 2010, the vertical system was also revised, and the new configuration entailed at least one dispensary in each and every city based on the 1 for 500,000 people principle (TC Saglik Bakanligi 2014). To this end, the Ministry of Health closed down 15 dispensaries. As of 2012, the total number of dispensaries was 179 countrywide, 33 of which were in Istanbul (Cakir et al. 2014). These dispensaries function under the vertical system and are run either directly by the Ministry of Health or by intergovernmental organizations (i.e., the Istanbul Anti-TB Association).

Prior to the transition to the family medicine system, all diagnostic and treatment services for drug-susceptible TB patients were carried out by these dispensaries. TB patients were referred directly to dispensaries for the proper care, medication and follow-up for 6 to 8 months, free of charge. Dispensary doctors and/or healthcare staff asked TB patients to come to the dispensary so they could give the patients their daily medication, watch them swallow them and keep records on a daily basis. With the advent of family medicine, the responsibility for following up patients undergoing DOT treatment has been passed to family healthcare centers, marking the beginning of a new era in TB control. This leap forward in a way initiated the first phase of the abolishment of the vertical system and integration of TB activities into primary healthcare services. A circular officially announced this change. Article 4b of the Circular[2] reads as follows:

> …following the dispensary registration of the TB patient, the dispensary doctor refers the patient to his/her family physician. After giving information on the DOT application to the patient, the family physician speaks to the patient and his/her family regarding the patient's age, general situation, working life and social condition, and determines when, by whom (DOT observer) and where the most appropriate DOT application will be carried out.

[2] Circular on Directly Observed Treatment no. 2009/51 (Dogrudan Gozetimli Tedavi Hakkinda Genelge no. 2009/51) http://www.saglik.gov.tr/TR/belge/1-9507/200951-sayili-dogrudan-gozetimli-tedavi-hakkinda-genelg-.html (date of access: 13 September 2015)

This article attempts to make sense of what the FPs in Istanbul think about TB and DOTS and how they apply it in their daily routines. In broad terms, the study aims to discuss how TB control in Turkey has been affected by the family medicine system and what the likely consequences of this transition will be on the Turkish National Tuberculosis Program in the long run. The article begins with my observations of family physicians and family healthcare workers in their daily practice, focusing mainly on predicaments in terms of TB case management. The second part depicts how DOTS in general and DOT in particular are misunderstood and misinterpreted in many ways. The final section analyzes the potential threats the new system poses to the future of treatment outcomes and the National Tuberculosis Program at large.

Materials and methods

The data for this article are derived from the qualitative part of my dissertation for which I carried out research in seven dispensaries in Istanbul between January and December 2011. The dispensaries were chosen by considering both the neighborhoods with high TB incidence and also the distributions according to the Anatolian and European sides of the city, also taking their administrative status into account, i.e., whether they are run by the Ministry of Health or the Istanbul Anti-TB Association.

I conducted semi-structured interviews with 30 healthcare professionals, including 10 dispensary doctors, 10 family physicians and 10 family healthcare workers, and 17 informal interviews with different healthcare professionals. I recruited family physicians and family healthcare workers among those to whom TB patients had been referred; family physicians without registered TB patients under their care were excluded from the study. Therefore, I applied both purposive and snowball sampling techniques. All formal interviews were tape recorded and transcribed. Verbal consent was obtained from each participant. Following the transcriptions, themes were codified and subjected to thematic analysis. The study was conducted with approval from the institutional review board at Istanbul University.

Results

New policy, new system, new problems

Patients' adherence to the treatment regimen essentially relies on their commitment to stay on a long-term therapeutic plan (ironically called the "short course," which lasts a minimum of 6 to 9 months) as well as the behaviors of healthcare providers (Munro et al. 2007; Xu et al. 2009; Mishra et al. 2006). Therefore patients' understanding of the duration and efficacy of available treatment together with potential side effects of anti-TB medications is a key to success. A welcoming and patient-friendly environment in health facilities also helps. Adherence is substantial insofar as it can determine the treatment outcome. Thus, in TB case management, the physician's constructive approach toward and sufficient allocation of time for the TB patient after diagnosis are crucial.

Unfortunately, most of the FPs interviewed reported that the approximate time they could spend with each of their patients was about 5 min. In an FP's words:

> Well, frankly I don't have the time…For instance, I examined 75 patients yesterday…And then the TB patient comes.…OK, I try to sort it out when there is a problem but "how are you, are you OK?" this and that…If I say that, the next one waiting in the queue will get angry. So there is no time for everything, you know. One will overweigh the other. (Female, FP)

Another family physician made a similar remark by saying "one examination does not take more than five minutes," underlining the fact that "the amount of time I give TB patients is the same as for every other patient."

In short, FPs said that they did not have much time to follow up with TB patients, much less time to deal with any possible problems those patients may have.

Family physicians view TB patients through different lenses. Unaccustomed to the requirements of the long-term follow-up, FPs treat them like "ordinary others." Patients who disappear before completing their treatment cannot be followed because of the FPs' busy work schedules with polyclinics admitting up to 80–100 patients a day; they do not have time for contact tracing even though TB poses a considerable threat to close contacts. On the other hand, doctors in dispensaries stress that they are able to give more time to their patients in order to inform them about both the disease and treatment procedure in detail. Ostensibly this makes sense because they deal only with TB patients, no one else. All in all, for FPs, TB patients are among those considered "difficult." Following them up at family healthcare centers is seen as "drudgery." They basically feel that the DOT job has been "saddled on them." There are even those who say taking care of TB patients "is not a job to be done even if they pay extra."

DOT or what?

Beyond allocating enough time, some of the FPs and healthcare workers mentioned how uncomfortable they felt with the TB patients referred to them because of the lack of enough space, personnel and equipment.

> There is no specific DOT room here. The polyclinic is narrow; the window is not always open. Our room is next to the vaccination room. There are babies, pregnant women and elderly people outside the examination room. Honestly I try to send the patient away as soon as possible. I answer his/her questions briefly.

DOT rests on the premise that patients should take all medications at once and under the supervision of healthcare personnel mainly because of the length of treatment and difficulty swallowing pills (Macq et al. 2003). In the initial phase of treatment in which sputum conversion has not yet been achieved, this is of more significance (Mishra et al. 2006; Blomberg et al. 2001). Since there are only a handful of first-line anti-TB drugs available and developing drug resistance is a threat concerning intermittent treatments or defaults, DOT is the main component on which experts rely.

In some family healthcare centers, pills were simply handed out to the patients who otherwise were expected to take them under the supervision of the healthcare professional. In other words, the patient was not observed while taking their pills. Referring to one particular patient, a nurse midwife reportedly said:

> We had a patient. He had lost so much weight. He was struggling to take his medications. A handful of medicine, of course…There were moments where he was taking 10 minutes to take one tablet. First, we gave it in the pregnancy room. We waited and waited, then took him to the injection room. We saw that there is also not good enough. Later on, we relocated him to the blood-drawing room. But it was taking longer and longer. We saw that this is not working, we started handing the medication to him and sent him home.

In fact, TB patients were sometimes even directly told to "take these and go and take them at home." On the same topic, a dispensary doctor revealed a story of a patient:

> There are patients who go to the dispensary every day, but the medicines are handed to them and they are told 'go take them at home.' This person goes there every day for, let's say, 180 days, can you believe; in snow, winter and summer! That is to say, why are you sending them then, why are you asking them to come back every day? Since you get him to take the medicine at home, give it to him or do not even interfere, we shall give him the medicines monthly, it was like this in the past.

Sometimes medications are not even given regularly. Only one FP I interviewed asserted "they try to give medicines regularly on a daily basis." However, after leaving her office, I met with a nurse who refuted the doctor and explained it as follows:

> Normally the patient is supposed to come and we are supposed to give the pills to him/her and observe while he/she is taking them. But for every patient, there are ones who don't come, so we give the medicines to their relatives. Because of this it is not carried out regularly.

The inconvenience caused by the existence of a TB patient at family healthcare centers is quite obvious. In one instance, the plastic cups TB patients used to take their medication were considered a problem and a long-running discussion ensued as to whether or not these cups should be considered medical waste or simply regular garbage. In the end, they agreed on defining them as "medical waste." In another family healthcare center, the healthcare staff put aside the writing pen that the TB patient used to sign the registers, and no one touched it afterwards. After the patient left, everyone washed their hands and opened the windows. The nurse also suggested to the patient that "he should put sheets and towels aside and disinfect the dishes with bleach." Another nurse reported that they did not "even want to allow patients into the building":

> Patients come with their water bottles anyway. They show up and I go out with pills on my hand. I let them take the pills outside and hand over the rest of the pills as well. I don't want them to be inside; there are babies, pregnant women, everybody is here…

Interestingly, a dispensary doctor also mentioned that he heard some complaints from a patient who had been yelled at to "get out" and was subsequently expelled as he entered the FP's room. The patient's questions had not been answered properly, nor was he allowed in when he needed something.

The underlying problem with many of these accounts is that these patients are assumed to be "contagious" a priori. According to the current practice, patients are referred to the nearest dispensaries in the area where they live/work. There, the dispensary doctor runs the required tests and initiates the treatment based on the physical examination and type of disease. Then the doctor refers the patient to his/her family physician for follow-up and asks the patient to come back once a month to evaluate the progress. If the patient is diagnosed with pulmonary TB and takes medications regularly for about two weeks, he/she is not infectious any more.

However, information on the type of TB and duration of initial treatment at the dispensary is missing during the transfer of the patient file to the family healthcare center. Thus, when a TB patient shows up in front of the family healthcare center's door, nobody has any idea about the actual status. Limited knowledge and lack of experience with TB, accompanied by

the fear of "drug resistance" of healthcare professionals at family healthcare centers, lead them to keep the TB patients as far away as possible from other patients and to treat them all as "contagious." Fear is so paramount that some FPs believe it would be more convenient if "the patient's relative rather than the patient himself/herself" would pick up their medicines. According to a nurse's own evaluation, there have been TB patients who "after coming once, they have never seen him again." It is hard to imagine, but some FPs completed a patient's treatment without seeing him/her a second time.

Conclusion

As the quotes from the interviews revealed, family physicians and health practitioners working in family healthcare centers do not ask their patients to follow DOT as strictly as dispensary doctors and their health staff do. Since they are solely engaged with TB patients, dispensary doctors are able to provide a sufficient amount of time for each TB patient in order to inform them extensively about the features of the disease, prognosis and details about the treatment including the potential side effects. During examinations, they are more likely to take long periods of time to explain why DOT is the most important component of the existing treatment while working hard to convince the patients and answer all their questions. Dispensaries are capable of providing patients with regular treatment.

For this very reason, dispensary doctors are not willing to accept any requests to change the daily treatment routine, which would otherwise mean that the patient only took their medication once a week or less. This group of physicians closely follows up their patients on a daily basis; they call to convince them to come to the clinic if they do not show up. There are doctors who go so far as seeking support from the police if they face resistance to treatment. As a result of their commitment, countrywide treatment default rates have gradually dropped (TC Saglik Bakanligi 2014). Undoubtedly, the contribution of this meticulous and persistent attention is significant in reaching a successful point in terms of TB prevalence.

On the other hand, in practice what is understood about DOT at family healthcare centers is entirely wrong. Due to the lack of appropriate physical infrastructure at family healthcare centers and inadequate information on TB and DOTS, medicines are not given to patients on a daily basis, even though this should be the case by definition. De facto practice is based on a few days, weekly or longer, even "monthly DOT," but definitely not daily. This basically translates into "no DOT is applied" in practice.

However, we can question how realistic it is for patients to come to a healthcare facility "every single day" for months and receive medication under proper medical supervision. These problems with the system are the reasons that the arrangement of the treatment protocol is carried out in a more "understanding and flexible" manner. Of course, seeing the patient only once or allowing a patient's relatives to pick up the medicine is not acceptable by any means. However, finding ways to be sensitive to difficulties that patients face as a result of DOT standards, or taking their priorities into consideration, would be a reasonable approach. Offering an acceptable option for patients who try to get medical treatment for a disease that brings about serious hardship affecting their whole life is an issue that requires further attention.

Discussion

According to the Health Transformation Program, all vertical programs would be abolished, and their activities would be integrated in the primary healthcare system as a part of a modern, if not trendy, approach to infectious disease control (Raviglione and Pio 2002; Uplekar and Raviglione 2007). In fact, anti-TB dispensaries have no room in the existing primary healthcare system. On paper, community health centers located in every district in a city carry out TB activities. Justification of the equivocal existence of dispensaries rests on the fact that the incidence of TB in Istanbul is still unacceptably high. Until this trend has been reversed, it is assumed that the government will not take the risk of locking the dispensary doors.

The transfer of the responsibility to follow-up TB patients to family healthcare centers is in a way an initial step toward the overall integration of TB activities into the primary healthcare system. However, contrary to expectations, it has the potential to jeopardize the successful trend in the struggle against TB. The overall picture is not as rosy and promising as claimed by Yildirim and colleagues (Yildirim et al. 2013). This study is highly relevant as it provides clues to the future of Turkish TB control. Moreover, the findings of this research are also consistent with the findings of a recent qualitative study focusing on the consequences of the family medicine system in Turkey (Turk Tabipleri Birligi 2013). FPs do not have up-to-date knowledge on TB for coping with TB patients and providing them with adequate and timely treatment. Besides, DOT is an extra burden for them. Contact tracing is not carried out, which can possibly lead to further spread and may also promote the development of drug resistance. As the interviews clearly reveal, family healthcare workers at family healthcare centers also have a tendency to negatively label and/or stigmatize TB patients, which would have an impact on TB patients' health-seeking behavior in the long run.

A small but practical step forward for policy makers could be an attempt to create a system that will provide the submission of detailed information about the type of TB, whether it was pulmonary or non-pulmonary, along with the date of

treatment initiation while referring them to FPs. At least such an effort could reduce the fear associated with TB, particularly the fear of transmission. Without that fear and panic, healthcare providers would be less likely to stigmatize TB patients, and patients would feel less frustrated by the unwelcoming environment they come across at family healthcare centers.

It is worth noting that the level of knowledge on TB and DOTS is far from sufficient among family physicians. Vocational training is needed. Another practical step could be the preparation of "concise TB guidelines" for use by FPs throughout the country. Due to their overwhelming workload and multiplicity of health conditions encountered in their daily practice, it would be realistic to have a condensed version of the actual TB guideline.

Based on the research presented here, it is clear that actual implementation of DOT has the potential to jeopardize TB control activities in the near future and risk lives unless nuanced interventions are made in the system. Integrating a vertical system into the primary healthcare structure could be a programmatic goal to be achieved in the long run; however, given the existing circumstances, the system is far from ready to close down the dispensaries. History provides an overwhelming lesson about the high cost countries have paid for intermittent or lax TB control activities. Turkey had long and exemplary success in TB control culminating in the declining incidence and high rates of treatment success and cures. However, before they can claim victory and move on, Turkey needs to take a much closer look at how abolishing vertical systems has indeed worked.

Compliance wih Ethical Standards

Conflict of interest Yesim Yasin declares that she has no conflict of interest. Selma Karabey declares that she has no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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