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'They prefer hidden treatment': anti-tuberculosis drug-taking practices and drug regulation in Karakalpakstan

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SUMMARY

SETTING: The joint Médecins Sans Frontières/Ministry of Health Multidrug-Resistant Tuberculosis (MDR-TB) Programme, Karakalpakstan, Uzbekistan.

OBJECTIVE: Uzbekistan has high rates of MDR-TB. We aimed to understand patients' and prescribers' attitudes to anti-tuberculosis drug prescription, regulation and drug-taking behaviour.

METHODS: Participants (12 patients, 12 practitioners) were recruited purposively. Data were gathered qualitatively using field notes and in-depth interviews and analysed thematically.

FINDINGS: Our analysis highlighted two main themes. First, shame and stigma were reported to increase the likelihood of self-treatment and incorrect use of anti-tuberculosis drugs, most commonly at the initial stages of illness. A health system failure to promote health information was perceived, leading to wrong diagnoses and inappropriate therapies. Motivated by shame, patients hid their condition by resorting to drug treatment options outside the programme, compounding the risk of chaotic management and dissemination of erroneous information through lay networks. Second, positive influences on treatment were reported through patients, practitioners and peers working effectively together to deliver the correct information and support, which acted to normalise TB, reduce stigma and prevent misuse of anti-tuberculosis drugs.

CONCLUSION: Effective case finding, patient support and community education strategies are essential. Patients, practitioners and peers working together can help reduce stigma and prevent misuse of anti-tuberculosis drugs.

KEY WORDS: MDR-TB; Uzbekistan; stigma; qualitative

MULTIDRUG-RESISTANT TUBERCULOSIS (MDR-TB) is defined as TB that is resistant to the two most powerful first-line anti-tuberculosis drugs, rifampicin (RMP) and isoniazid (INH). MDR-TB is an emerging global problem, affecting an estimated 3.5% of new TB cases and 20.5% of retreatment cases.[1] Drug resistance is fuelled by many factors, including the quality of anti-tuberculosis medications, poor adherence to treatment, ineffective treatment and retreatment regimens,[2,3] and poor hospital infection control practices. In addition, direct access to arbitrary use of anti-tuberculosis drugs for patients through the private market has been implicated in treatment failure and the development of drug resistance in high-burden countries.[4] For example, in Tbilisi, Georgia, anti-tuberculosis drugs, including second-line agents used to treat MDR-TB, were widely available without prescription at pharmacies.[5] Strategies to ensure effective drug management and supply form a major component of the World Health Organization's (WHO's) Stop TB Strategy.[6] It has been concluded that policies regarding the sale and distribution of anti-tuberculosis drugs should receive more attention in the global strategy to control drug resistance.[7]

Médecins Sans Frontières (MSF) has treated MDR-TB in collaboration with the Ministry of Health (MoH) in Karakalpakstan, Uzbekistan, since 2003. Under the MoH National Tuberculosis Programme (NTP), treatment for drug-resistant TB (DR-TB), at least in the intensive phase, is most commonly delivered on an in-patient basis. All areas of Uzbekistan reportedly now have access to rapid molecular diagnostics and WHO-recommended treatment regimens. In Karakalpakstan, treatment is delivered in the community, with all cases directly managed by the MoH. MSF provides technical support to clinicians, psychosocial support, medications for side effects, laboratory coordination and additional logistic sup-

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port, including infection control, nutritional support and assistance with adherence strategies.

Uzbekistan has some of the highest reported MDR-TB rates in the world, with 23% of new and 62% of retreatment TB cases identified as MDR-TB.[8] Treatment for TB outside the standard NTP is known to occur, despite a national drugs policy that prohibits the sale or use of anti-tuberculosis drugs without prescription from a TB specialist clinician or clinic.[9,10] We mapped all of the 400 private and MoH-affiliated pharmacies in Karakalpakstan, finding evidence in some that it was possible to purchase drugs used to treat susceptible TB without prescription—most commonly INH, RMP and streptomycin.

The Uzbekistan Government has acknowledged the need to improve the regulatory system for drug products and pharmaceutical activity.[9] Uzbekistan already has effective regulations, in terms of both policy and practice, for narcotic and psychotropic drugs. These drugs, detailed in government-compiled lists, can be sold only under a special licence. A monthly audit is conducted under the relevant law of medications sold against prescriptions provided to pharmacies. The government is currently upgrading the anti-tuberculosis drug regulation system for quality control and state registration of drugs to meet the norms and standards of the European Union and the WHO. For example, regional branches of the National Agency for Regulation of Drug Products are being established to guarantee adequate quality control.

With the present momentum for improvements in drug regulation in Uzbekistan, there is a need for a better understanding of anti-tuberculosis drug use. With the impending availability of new drugs for TB, it is essential that appropriate policies are formulated and implemented to prevent their misuse. While there is some awareness about the challenge of anti-tuberculosis drug regulation in the MoH and the private sector, examination of local anti-tuberculosis drug use from the perspectives of patients and practitioners is critical. In particular, understanding patient and practitioner beliefs, knowledge and behaviours is crucial in revising drug regulation policies.

We conducted a qualitative study to assess current policy and practice for the regulation of anti-tuberculosis drugs to understand the perceptions, behaviour and experience of patients and practitioners in Karakalpakstan related to the use of TB medication. We aimed to understand and conceptualise patients' and prescribers' attitudes to anti-tuberculosis drug prescription, TB drug-taking behaviour and the problems of TB drug regulation in a high MDR-TB burden context.

METHODS

Research design

We used a flexible participatory technique in which data were gathered from patients and practitioners using in-depth interviews guided by topic-led questions as well as field notes. Interview questions were based on themes relevant to the study aims and a literature search of studies, laws, policies and audits related to anti-tuberculosis drug use and the role of the private market. Following standard qualitative interview procedures, the order of questions was driven by the nature of participant answers, leading to the modification of the wording of the questions and the order in which they were asked during the interviews. The primary investigator conducting the interviews was from outside the treatment programme.

'Fair dealing', which searches for and represents participants' views as dispassionately as possible and without moral judgement, was achieved by seeking a wide range of perspectives from specialised to general practitioners within the domain of caring for persons with DR-TB.[11] Attention to negative cases was pursued, meaning that contradictory or unexpected findings were actively sought and explored to ensure that predominant themes were a true reflection of participant responses.

Setting and sample

The study was conducted under the joint MoH/MSF TB programme in 2012 in three administrative districts of Karakalpakstan: Nukus, Takhiatash and Hodjeley. Recruitment of 24 participants (12 practitioners and 12 patients) facilitated by a programme manager in the country. Initial identification for recruitment was contingent on the inclusion criteria: new patients, patients who had completed treatment and chronic patients were eligible, while TB specialists, non-specialist doctors and pharmacists working in the MoH, for MSF or the private system were included where possible.

A snowball technique was used to recruit practitioners and patients to increase the uptake of participants who were difficult to reach due to communication and time limitations for public engagement with the research. A project manager/gatekeeper approached participants with an information sheet that outlined the study. Three people (one patient and two practitioners) refused to participate due to unavailability or unwillingness. Another patient agreed to participate, but did not attend the appointment and was unavailable thereafter. Purposive sampling enabled recruitment of individuals with sufficient knowledge and experience of the study topic to enable the development of generalised information on processes and typical patterns of meanings.

Practitioner participants were mainly physicians working in the TB sector (MSF and MoH), but also general practitioners in primary health care and one MoH pharmacist. Patient participants were all DR-TB patients who had been enrolled in the NTP managed by the MoH, in some cases with MSF support. Although a relatively small number of participants were interviewed, data collection was stopped when no new information was being generated from additional interviews.[12]

Data collection

Informed consent was sought both before and at the time of the interview using an information sheet translated into the local language (Karakalpak) stating the purpose of the study and the voluntary nature of participation. Participants also gave written consent on the day of their interview. Interviews were audio-recorded in a private space, usually at the health facility where the practitioner worked or where the patient currently or had previously attended. All interviews were conducted with an interpreter to translate questions and responses from English to the local language. The interpreter was briefed before and after each interview to ensure the highest quality of data extraction. All interviews lasted between 45 and 60 min.

Although participants were able to stop their interview at any point, no one chose to do so. Confidentiality was assured for all participants, with the names of the respondents and all data referring to them being replaced by codes (D for physician, TBS for TB Specialist, PH for Pharmacist, GP for General Practitioner and P for patient). Electronic data were password protected.

Data analysis

From the moment data were generated during the interviews, the 'thinking and theorising' of data analysis began.[13] Data were initially managed through verbatim transcription of all recorded conversational interviews. Silences and emotional cues (e.g., sighing, laughter) in the audio recording of the interview were noted.

Open coding of interview transcripts allowed text to be reviewed and re-reviewed line by line so that the 'tagging' of words, phrases or paragraphs emerged into codes that were constantly compared and refined, revealing the experiences of the participants rather than being externally imposed.[14] The first author sorted codes and categories by interconnected themes or concepts,[13] and discussed these with the second author. Codes emerged inductively; themes and categories were drawn from respondents to make 'implicit belief systems explicit in order to generate some theoretical insight'.[15] The decision to perform manual rather than electronic coding was partly related to the relatively small sample size and also to the value of interacting with the data in a way that promoted continuous refinement of interpretations and deeper understanding.[12]

Participant validation involved 10% of each participant's coded interview transcript chosen at random being checked by them to ensure that the researcher's documentation and analysis were not disputed. Researcher reflexivity and awareness of the potential for 'personal or intellectual biases' were exercised,[16] together with the use of field notes and relevant literature.

Table 1 Participant characteristics

Participant characteristic	Participants *n*
General practitioner	2
TB specialist	9
Pharmacist	1
Drug-resistant TB patients	
New patients	6
Chronic patients	4
Completed treatment	2

TB = tuberculosis.

Ethics

Ethics approval was granted by the MSF Ethics Review Board (Geneva, Switzerland) and the Bioethics Commission of the Ministry of Health of the Republic of Uzbekistan (Tashkent, Uzbekistan).

RESULTS

The response rate was 86%. Participant age ranged from 22 to 60 years, with equal numbers of males and females. Table 1 shows the characteristics of the participants.

We present the main findings by negative and positive influences on anti-tuberculosis treatment. Both influences highlighted the likelihood of incorrect use of anti-tuberculosis drugs and the potential to prevent self-administration or poor management of TB. We illustrate our findings through quotes from the participants (Tables 2 and 3).

Negative influences on anti-tuberculosis treatment

Negative influences include factors that increased the likelihood of self-treatment, incorrect use and chaotic management of anti-tuberculosis drugs. Key among these influences were shame and stigma, and incorrect lay knowledge.

Shame and stigma

The shame and stigma that patients expressed in having TB were a major contributor to the risk of incorrect treatment. Nearly all participants, both professional and patient, referred to these concepts as incentives for people with TB to seek self-treatment in

Table 2 Negative influences: illustrative quotes from participants

Shame, stigma and chaotic management
Physician 1 (TB specialist): Then we have stigma, meaning that it is a very bad form stigma means not telling others you have TB or getting treatment somewhere.
Patient 11: There are, for example, people of higher social levels they don't want to go to hospitals, they prefer hidden treatment when they buy drugs at pharmacies they do it secretly.
Chaotic management by practitioners and patients
Physician 7 (TB specialist): I visit polyclinics and show [the general practitioners] their mistakes; they still repeat them when I visit them next. It means, that people do not feel themselves responsible.
Patient 12: When I contacted a doctor he said I got a bit cold. This and that, it had adhered to your lungs, it is enough to take these and those injections, but I couldn't get the full treatment
Patient 7: People say to go to a sorceress. If they believe them they may do this or that. It easier than taking drugs, that's why they prefer that way. People always seek easier ways. That's why they stop the drugs and go to them.
Incorrect knowledge
Physician 6 (TB specialist): And if we talk about those who self-medicate from pharmacy, they usually say 'my neighbour had TB and I get the same treatment from them, or a relative had TB, or someone at home'.
Physician 1 (TB specialist): They take without prescription, because they go to some events like funerals, weddings, that time they may hear 'I got cough, and tried this drug'. Says he/she got tubazide [proprietary name for isoniazid], isoniazid [TB drug used in standard regimen] and advises them to others. Do you get me? They gather together during these events. They say 'I have cough', 'your cough is very bad', 'a man in a drug-store told me, advised me, I got this and got cured'.
Pharmacist 10: At pharmacies? Many drugstores sell ethambutol, rifampicin is easily available, isoniazid, and I think it's only pyrazinamide which is not delivered.
Physician 10 (TB specialist): Yes, yes, yes, free availability sometimes they disappear for example pharmaceutical companies don't have them sometimes it happens and it is difficult to find them in drugstores and their prices increase now they are available yes available.
Physician 4 (TB specialist): Well it's up to the patient because if the patient says 'I will take I will find' he may do this.

TB = tuberculosis.

Table 3 Positive influences: illustrative quotes from participants

Knowledge about successful treatment
Physician 1 (TB specialist): We should work together with GPs… We should make it better in polyclinics and work with, umm other specialist, neurologists, with surgeons.
Patient 5: I wake up in the morning, thank God that I am good, and recently we started adding words like 'when I finish the programme I will be healthy'. We live with these thoughts, with the idea that the treatment will have good effect on us.
Patient 11: These drugs are very good! If you take them you will be cured, I believe in their power when they told me they would treat me . . .I agreed despite all the difficulties.
Patient 5: We are getting better thanks to these drugs. We. . . ummm. . .how to say it. . .I. . .umm. . .we, women here are taking drugs together and . . .ummm we talk to each other having no secrets.
Patient 1: I saw a picture of my lung I got happy. I believe in the effect of these drugs.
Health practitioner, peer and policy support
Physician 7 (TB specialist): A doctor should pay much attention and time to the patient; I mean patient should see that not only his family wants him to recover but doctors too. Only this kind of attitude may help get him cured . . . if a doctor loses a patient's trust, patient will not give him even a chance to treat.
Patient 6: There have been many of them having problems at home, when they don't have peace at home, they can't take them at home, I can easily be a friend to anyone – we take drugs together here.
Physician 5 (TB specialist): To prevent this. . . to stop selling, we need to add. . .include to our work the Ministry of Health, the Cabinet of ministers, tax committee, customs, Government. If the ministry, tax committee and customs agree to join you this will be successful, fines will be enough for others to stop selling.

TB = tuberculosis.

order to avoid disclosing their status (Table 2, quotes 1, 2).

Feelings of shame and stigma were also found to lead to chaotic management of anti-tuberculosis treatment by patients, general practitioners, and more widely in primary care, a point stressed by patients and practitioners. Participants differentiated between self-medication with anti-tuberculosis drugs and mismanagement of these drugs by doctors or radiologists working outside the official NTP; however, all participants associated a lack of knowledge about effective treatment of TB with the chaotic management of patient care (Table 2, quote 3). For patients, poor management by practitioners was the predominant issue (Table 2, quote 4). Of note, where patients were already in the official treatment programme, treatment interruption due to side effects or quality of care was not seen as a risk factor for seeking alternative anti-tuberculosis drugs, especially where disillusionment due to drug side effects was the main reason for a treatment break. Instead, the inclination at this stage was towards seeking traditional healing options such as ingestion of dog fat or remedies from traditional healers (Table 2, quote 5).

Incorrect lay knowledge

The second factor influencing patients' tendency to seek treatment outside the NTP involved what could be termed as incorrect lay knowledge. Information conveyed through a neighbour, relative or lay community network during collective events such as weddings or funerals was perceived by patients as instrumental in the proliferation of incorrect advice on treatment for TB. Such information was implicated in decisions to seek treatment outside the NTP, especially where lay networks indicated that a quicker treatment solution was available (Table 2, quotes 6, 7).

Risk of self-medication was highest before referral or entry into the NTP. While access to anti-tuberculosis drugs was prevalent, common knowledge about drugs specifically used to treat TB that is resistant to first-line drugs was limited.

In terms of common knowledge, most patient participants demonstrated familiarity with the drugs used to treat susceptible TB as opposed to TB resistant to first-line drugs (Table 2, quote 8). Doctor

and patient participants referred to the easy availability of anti-tuberculosis drugs as a factor contributing to self-medication (Table 2, quotes 9, 10). The availability of anti-tuberculosis drugs outside the NTP and incorrect lay knowledge about anti-tuberculosis treatment, coupled with shame and stigma surrounding TB, have a bearing on developing policy towards regulation of anti-tuberculosis drugs.

Positive influences on anti-tuberculosis treatment

Positive influences on anti-tuberculosis treatment highlight how the correct information and support communicated between patients, practitioners and peers working together effectively, and with strong policy support, can contribute to increasing familiarity with TB. This strengthens beliefs in the treatment as a cure, reduces stigma and prevents misuse of anti-tuberculosis drugs.

Knowledge and belief about successful treatment

In terms of overcoming the chaotic management of treatment, all respondents suggested knowledge about successful anti-tuberculosis treatment to be a key factor. This was noted not only in terms of understanding the association between treatment and cure from a doctor-patient perspective, but also in the context of good communication between specialists and general practitioners contributing to better management of treatment regimens for TB (Table 3, quote 1). All participants referred to entry into the NTP as helping prevent self-medication. Once a patient had entered the treatment programme, the availability of free drugs, perceived as being of high quality and giving good results, was a positive feature for all participants (Table 3, quotes 2, 3). Both patient and practitioner insights on the control of anti-tuberculosis treatment described easy access to medicines and the supply of formal treatment as essential to stopping self-medication.

Other predominant ideas from patients and practitioners were associated with treatment adherence and understanding the strength of the drugs used to treat DR-TB. Ways to ease the side effects of anti-tuberculosis drugs described by patients were presented as means of sustaining treatment, indicating that peer support can increase patient awareness of the importance of completing treatment (Table 3, quote 4). Seeing positive outcomes arise through treatment completion and cure strengthened patients' belief in treatment. In particular, the relationship between knowledge, belief in treatment and communicating completion of treatment and cure was stressed. One patient highlighted the education that the programme could offer through 'seeing' the disease; for example, the value of seeing the X-ray used as part of diagnosis (Table 3, quote 5).

Health practitioner, peer and policy support

All respondents stressed the value of communication and doctor-patient support as a safeguard against alternative hidden treatments. There was evidence that this patient-centred approach built up the confidence, trust and motivation necessary for patients to continue with appropriate treatment regimens (Table 3, quote 6). Peer support, involving sharing knowledge, experience and encouragement, was presented as valuable and part of patient solidarity. Of note, this support was not reported to have reached the home; instead, the place where treatment was carried out was conceptualised as the place of sanctity for patients (Table 3, quote 7). Peer support and patients' drive to overcome the difficulties of treatment emerged as potentially being able to normalise TB. These factors should be nurtured as key components in patient-centred care, alongside effective case finding, tailored treatment and adherence.

On the question of better administrative, institutional and legal controls over the regulation of anti-tuberculosis drug use, political leadership toward directives for more stringent control for specific anti-tuberculosis drugs was indicated (Table 3, quote 8).

In relation to indicators for effective treatment, the predominant ideas and majority themes found in both patient and practitioner responses showed that patients were more likely to perceive treatment as effective if they were correctly educated about the merit of anti-tuberculosis drugs and experienced the benefits of treatment completion. This in turn was seen to endorse the value of the NTP. Alongside the 'test and treat' health education message, 'complete and cure' was seen as equally necessary.

DISCUSSION

Patients reported misuse of anti-tuberculosis drugs to be most likely at the initial stage of their sickness and treatment journey. Motivated by the shame of having TB and the inherent social stigma, patients chose to hide their condition by resorting to drug-treatment options outside the NTP.[17] Self-treatment appeared less likely once patients had engaged with the programme, underlining the need for a strong case-finding component in the approach to anti-tuberculosis treatment. Finding patients and initiating correct diagnosis and treatment is critical to preventing default to self-treatment and promoting a successful outcome. Interruption of treatment was not a risk factor for seeking alternative anti-tuberculosis drugs, but did initiate the use of alternative traditional treatments. Chaotic management of TB care was reported to be connected to instances where the primary care practitioner was presented with cases they did not know how best to treat.

The value of a treatment programme characterised by free, accessible and supportive patient-centred care was evident as an important determinant for sustaining effective treatment. As previously reported through studies looking at patient-centred care as positive for effective treatment, our findings support focus on the patient as key to maintaining good treatment practice, both for primary care doctors involved in the NTP and for patients engaged in receiving effective anti-tuberculosis treatment.[18] Likewise, doctor-patient trust and support were deemed significant in preventing the misuse of drugs, and therefore contributed to adherence.[19] In particular, Fiscella et al. established that physicians' verbal behaviour during the doctor-patient encounter was associated with trust by both practitioners and patients.[20]

As supported by a growing body of evidence,[21] patients saw peer support and belief in treatment as vital components of the NTP. The next challenge is to extend this support and the positive experience of anti-tuberculosis treatment to the home and community environments. This effort should involve targeted community sensitisation and supervised home-based treatment where indicated,[22,23] in particular where social gatherings enable the transmission of incorrect knowledge.[24]

Knowledge about TB and treatment should be an important component of future drug regulation strategies.[25] The effective dissemination of correct knowledge can catalyse change. It is apparent that poor knowledge and a sense that cure is difficult or that treatment can fail can lead to stigma and non-disclosure of infection.[26] The communication of correct knowledge and understanding between patients, between patients and their doctors, and between doctors is therefore essential for uptake and completion of effective anti-tuberculosis treatment.[27]

Knowledge about and access to drugs used to treat susceptible TB in the private sector was confirmed as a result of a pharmacy mapping exercise and patient knowledge drawn from the in-depth interviews. However, drugs used predominantly to treat TB resistant to first-line drugs were not as available or as well known by patients. Political leadership is an essential consideration of the new policy development towards successful TB drug control, especially in the light of new drugs in the anti-tuberculosis treatment pipeline.[28] Table 4 shows policy recommendations that we have drawn from our research.

Table 4 Policy recommendations

- Political influence should be exercised by the relevant government ministries and WHO for more stringent control of specific anti-tuberculosis drugs. Engagement between the public and private sector for this purpose is essential
- A free, patient-centred anti-tuberculosis treatment approach is equally important for effective regulation
- The system of drug regulation for narcotic and psychotropic drugs in Uzbekistan should be adapted for anti-tuberculosis drugs, especially for those that are vital for the treatment of drug-resistant TB
- Effective case finding, community education and patient support strategies should be included in programming to diminish the problem of shame and the desire for patients to seek treatment elsewhere
- Development of training and education programmes aimed at increasing clear guidance to general health practitioners, i.e., doctors, pharmacists and radiologists
- Inclusion of peer support in national TB programme strategies to enhance shared experience of anti-tuberculosis treatment and cure

WHO = World Health Organization ; TB = tuberculosis.

Limitations

Due to some patients' experience of the benefits of treatment, the potential for them to present only a very positive account has been considered in terms of objectivity from the standpoint of cure. However, patients' potential to articulate and draw on life stories related to a general engagement with treatment was well suited to the aims of the research. While the response rate was good, it is acknowledged that the participants approached may have been those easier to access by NTP staff. The reason for participant refusal was linked to time availability and general doubts about the research. Although private practitioners were not interviewed, insights into private and public health practices were seen through the perspective of all interviewees.

Participants may give responses that they think the researcher is hoping to hear; however, for this study, the researcher was sufficiently distanced from the programme to counter this effect. The study design could be seen as offering a unique chance for participants to express their views and tell their stories to an outsider who had no responsibility in the programme. As is characteristic of qualitative research, the data cannot be generalised to the population, but transferability to other research findings can apply.

CONCLUSIONS

The study was stimulated by practitioners' anecdotal evidence that the misuse of anti-tuberculosis drugs was prolific through self-medication and regimen mismanagement. Our findings highlight the risks for anti-tuberculosis drug misuse and the opportunities for prevention, and reinforce the need for political engagement with the public and private sector.

Stigma and shame and the desire for patients to seek treatment elsewhere should be addressed by the inclusion of case-finding and community education strategies in programming. A patient-centred treatment approach to TB achieves this aim, and is thus as important as the administrative regulation of drug treatment regimens. A decentralised treatment ap-

proach with stringent controls is the best solution for TB drug regulation. As first-line anti-tuberculosis drugs are perceived as being more misused than second-line drugs, stringent regulation of these drugs is a feasible and urgent next step.

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RESUME

CONTEXTE : Le programme conjoint Médecins Sans Frontières/Ministère de la Santé sur la tuberculose multirésistante (TB-MDR), Karakalpakstan, Ouzbékistan.

OBJECTIF : L'Ouzbékistan a un taux élevé de TB-MDR. Nous avons tenté de comprendre les attitudes des patients et des prescripteurs vis-à-vis de la prescription de médicaments anti-tuberculeux, les règlements et le comportement en matière de prise des médicaments.

MÉTHODE : Les participants (12 patients, 12 praticiens) ont été recrutés. Les données ont été recueillies qualitativement grâce à des notes de terrain et à des entretiens approfondis et analysés de manière thématique.

RÉSULTATS : Notre analyse a mis en lumière deux thèmes principaux. En premier, la honte et la stigmatisation se sont avérées augmenter la probabilité d'automédication et d'utilisation incorrecte des médicaments antituberculeux, le plus souvent au stade initial de la maladie. Nous avons constaté l'échec du système de santé à promouvoir des informations sanitaires, ce qui a abouti à de faux diagnostics et à des traitements inappropriés. Motivés par la honte, les patients ont caché leur état en recourant à des options de traitement médicamenteux de la TB hors du programme, majorant le risque de prise en charge chaotique et de dissémination d'informations erronées à travers des réseaux profanes. Deuxièmement, des influences positives sur le traitement ont été rapportées par les patients, les praticiens et les pairs travaillant efficacement ensemble afin de délivrer des informations et un soutien corrects, qui ont permis de normaliser la TB, de réduire la stigmatisation et de prévenir une mauvais usage des médicaments antituberculeux.

CONCLUSION : Des stratégies efficaces de recherche de cas, de soutien des patients et d'éducation communautaire sont essentielles. Les patients, les praticiens et les pairs travaillant ensemble peuvent contribuer à réduire la stigmatisation et à éviter le mauvais usage des médicaments de la TB.

RESUMEN

MARCO DE REFERENCIA: El programa contra la tuberculosis multirresistente (TB-MDR) ejecutado de manera conjunta por Médecins Sans Frontières y el Ministerio de Salud de Karakalpakistán, en Uzbekistán.

OBJETIVO: En Uzbekistán se observan altas tasas de TB-MDR. El estudio tuvo por objeto comprender las actitudes de los pacientes y de los profesionales de salud que los atienden, frente a las recetas y la regulación de los medicamentos antituberculosos y el comportamiento de toma de los mismos.

MÉTODOS: Los participantes se escogieron mediante un muestreo intencional (12 pacientes y 12 médicos). Se recogieron datos cualitativos a partir de las notas del terreno y entrevistas exhaustivas y se analizaron por temas.

RESULTADOS: El análisis destacó dos temas principales. En primer lugar, se encontró que la vergüenza y los estigmas aumentan la posibilidad de automedicación y de uso incorrecto de los medicamentos antituberculosos, sobre todo en las etapas iniciales de la enfermedad. Se percibió una falla del sistema sanitario para promover la información de salud, que da lugar a diagnósticos errados y tratamientos inadecuados. Motivados por la vergüenza, los pacientes ocultan su estado y recurren a opciones de tratamiento medicamentoso por fuera del programa, agravando así el riesgo de un manejo caótico y de diseminación de una información errada por conducto de redes generales de comunicación. En segundo lugar, se notificaron influencias positivas en el tratamiento por parte de los pacientes, los médicos y los pares que trabajan en conjunto de manera eficaz para difundir una información correcta y prestar apoyo, lo cual lleva a la normalización de la TB, la disminución de los estigmas y evita el uso impropio de los medicamentos antituberculosos.

CONCLUSIÓN: La búsqueda eficaz de casos, el apoyo a los pacientes y las estrategias de educación a la comunidad son primordiales. Los pacientes, los médicos y los pares que trabajan en colaboración pueden contribuir a disminuir los estigmas y evitar el uso incorrecto de los medicamentos contra la TB.