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Receiving healthcare for drug-resistant TB: a cross-sectional survey from Pakistan

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OBJECTIVE: To describe and quantify patients' self-reported experiences of receiving healthcare from Pakistan's Programmatic Management of Drug-Resistant Tuberculosis (PMDT) model of care, and to understand these experiences within the broader context of Pakistan's health system.

METHOD: This was a cross-sectional survey of patients attending three PMDT clinics in Khyber-Pakhtunkhwa Province in Pakistan.

RESULTS: The median consultation time at the PMDT clinics was 10 minutes. In their most recent visit to the PMDT clinic, 34.9% of patients spent >40% of their monthly income to access treatment. To specify, 71% of patients reported spending out-of-pocket for ancillary medicines and 44.7% for laboratory tests. In 10.5% of cases, medicines for drug-resistant TB (DR-TB) were dispensed without the patient attending the clinic. Only 43.7% of treatment supporters regularly accompanied patients to the clinic, and 6% supervised the patient's intake of medicines. Disbursement of financial support was irregular in 98.6% of cases. Only 6.2% of patients received their daily injections from a public facility, the rest went elsewhere.

CONCLUSION: Several shortcomings in PMDT services, including hurried consultations, irregularities in financial support, and gaps in Pakistan's broader health system undermined healthcare experience of patients with DR-TB. To improve health outcomes and patients' care experience these service gaps need to be addressed.

Drug-resistant TB (DR-TB) develops when the causative bacteria *Mycobacterium tuberculosis* become resistant to the drugs used for the treatment of primary (drug-susceptible) TB.[1] DR-TB is a difficult to treat disease.[2] Globally, DR-TB comprises less than 5% of all TB cases but results in a substantial burden for health systems, communities, families and individuals.[3] The treatment is demanding and is associated with frequent side effects, risk of non-adherence, loss of productivity, low cure rates and high mortality.[4,5] Pakistan is one of the 20 high DR-TB burden countries worldwide, with an estimated 25,000 DR-TB cases every year. The proportion of drug resistance is 4.2% in new TB and 7.3% in previously treated TB cases.[1] In response, the National TB Programme (NTP) in Pakistan launched the programmatic management of drug-resistant TB (PMDT) model of care in 2010, which is supported by the WHO and the Global Fund.[6,7] As part of this model, dedicated PMDT clinics were established in public tertiary hospitals at district level. This arrangement was instituted to enhance patients' geographical access to specialised PMDT clinics that provide a comprehensive and free-of-charge package of DR-TB services, including access to pharmacy and laboratory facilities in tertiary hospitals where these clinics are located.[6]

The PMDT package of health services includes clinical examination and ongoing management by a DR-TB physician; counselling sessions with a psychologist; meetings with the clinic pharmacist; and health education sessions for patients and their families.[6] Furthermore, a laboratory technician at each PMDT site assists patients to access tests such as blood investigations and chest X-rays from laboratories located in the tertiary hospital.[6–8] The PMDT clinics operate 6 days a week and patients are required to visit these clinics once a month to receive these services.[6,9] To supervise patients' daily intake of medication at home, the PMDT model introduced the role of treatment supporter, usually a family member.[6,9] The PMDT staff nominate a treatment supporter in consultation with the patient, and train them to supervise the patient's daily intake of medicines. Treatment supporters are expected to accompany patients every time they visit the PMDT clinic. Both the patient and their treatment supporter are paid a fixed amount per month to cover the travel costs incurred when visiting the clinic.[9] The programme allocation was Pakistani rupee (PKR) 2800 (US$20) for the patient and PKR2200 (US$15.8) for the treatment supporter (US$1 = PKR139, and purchasing power parity at 33.6 per international US$ at the time of data collection). Patients were further linked to a basic management unit (BMU) near their place of residence to seek treatment for minor side effects of DR-TB drugs, and to receive daily injections during the intensive phase of treatment.[6] The BMUs, including basic health units (BHUs) and rural health centres (RHCs) are public health facilities in Pakistan providing free primary healthcare.[10] The treatment success rate in the 2018 cohort of patients receiving health services from this model of care was 64%.[1] The Figure provides an overview of the PMDT model of care.

The purpose of the present study is to assess patients' experience of receiving the PMDT package of services in practice compared to how it was envisioned and designed at the policy and programmatic levels; and to shed light on the economic impact on patients while receiving these services. To achieve this objective, we conducted a cross-sectional survey at three out of the five PMDT clinics in the Khyber-Pakh-

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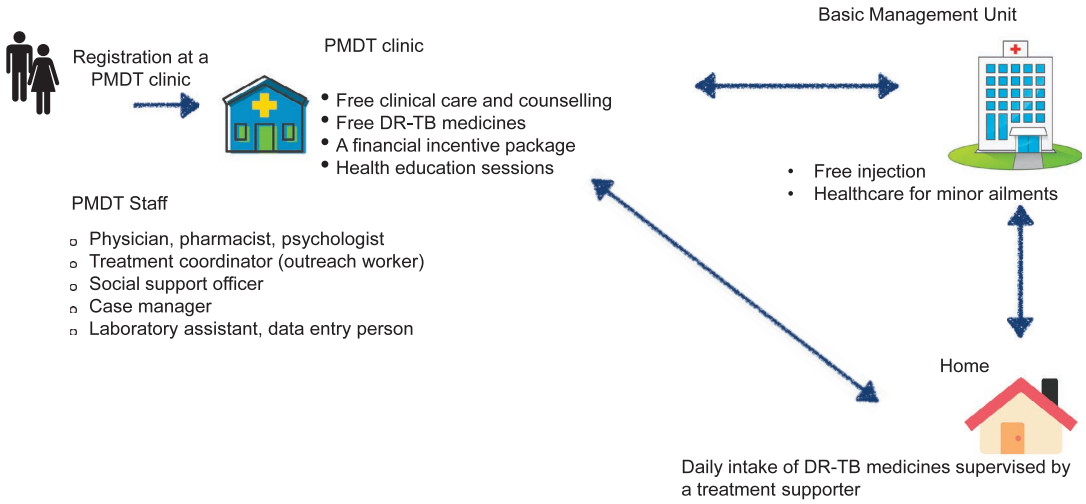

FIGURE The PMDT model of care. PMDT = programmatic management of drug-resistant TB; DR-TB = drug-resistant TB.

tunkhwa (KP) Province of Pakistan. DR-TB in KP contributes to 13% of the national TB burden in the country.[11] The KP Province was chosen for this survey study given the first author's familiarity with the local culture and ability to speak most local languages.

METHODS

This cross-sectional survey is part of a larger mixed-methods study examining healthcare practices at three PMDT clinics in the KP Province of Pakistan. The results of the qualitative investigation have been reported separately.[12] The survey participants shared the experience of receiving health services from a dedicated model of healthcare. All patients with DR-TB registered at the three study sites, either in the intensive (injectable) or the continuation (the post-injection) phase of treatment, were invited to participate in the survey. Newly diagnosed patients on their first visit to PMDT clinic were excluded. No patient refused to participate in the study; however, during busy outpatient days a few patients left before they could be interviewed. Therefore, out of a total of 161 eligible patients at the three study sites, 152 were surveyed (response rate 94.4%). At the time of data collection, both the longer (18–20 months' duration) and shorter (9–12 months' duration) DR-TB treatment regimens were being followed at the PMDT clinics as per WHO guidelines.[13]

Before administering the survey, participants were informed about the purpose of the study and provided with a plain language statement in Urdu (local language). The survey was administered to individual patients and/or a patient-nominated family member after providing informed written consent. Verbal consent was recorded and saved for participants not able to read and write. For patients aged <18 years, the survey was conducted with an accompanying adult family member. The survey was administered by the first author, and interviews generally lasted 30–40 minutes. Interviews were conducted in a private place within the hospital or at the patient's home to ensure confidentiality. Participants were not paid for participation in the survey. Data were collected between July 2018 and March 2019.

Survey respondents were asked about patients' travel and health services experiences during their most recent visit to the PMDT clinic, daily intake of oral medication and injections (during the intensive phase), the role of the treatment supporter in patient care, the impact of DR-TB on patients' income and productivity, costs associated with seeking healthcare and coping strategies adopted to manage treatment costs. Relevant demographic data were collected. The survey questionnaire was adapted from the WHO's "Tuberculosis Patient Cost Survey Questionnaire" to suit the local context.[14] Additional questions about the role of BMUs in DR-TB care, accompanying family members other than the treatment supporter, and details of loan sources were included to better characterise patients' experiences and spending in relation to accessing PMDT services. The questionnaire was translated into Urdu (local language) and back translated to English to assess the accuracy of translation, field-tested and revised for clarity and relevance.*

A descriptive statistical analysis was conducted in this study. Participants' baseline characteristics are summarised using means, median and range. The analysis focuses on three key areas: visit to the PMDT clinic; receiving the PMDT package of health services; and the financial impact on patients and their families as a result of accessing these services. The analysis was conducted using Microsoft Excel (Microsoft, Redmond, WA, USA) and Stata v10 (Stata Corp, College Station, TX, USA).

Ethics approval for this study was obtained from the University of Melbourne, Melbourne, VIC, Australia and the Health Services Academy in Islamabad, Pakistan. Additional permission for this study was obtained from the national and provincial (KP) TB programmes in Pakistan.

RESULTS

Of the 152 patients surveyed, 91 (59.9%) were in the continuation phase and 61 (40.1%) were in the intensive phase of treatment. Twenty-three (15.1%) patients were prescribed the shorter DR-TB regimen, while 129 (84.9%) were on the longer regimen. Table 1 shows the patient demographics.

Access and coverage of PMDT services

In this section, under three sub-headings, we describe how a visit to a PMDT clinic was managed by patients, their experience of

*Questionnaire available on request from the corresponding author.

TABLE 1 Patients' demographic characteristics (n = 152)

Variable		*n*	%
Sex	Male	77	50.7
	Female	75	49.3
Age, years	0–19	27	17.8
	20–39	71	46.7
	40–59	39	25.6
	⩾60	15	9.9
Marital status	Married	103	67.8
	Unmarried	32	21.1
	NA (<18 years)	17	11.1
Area of residence	Urban	32	21.1
	Rural	120	78.9
Education	No formal education	85	55.9
	At least 5 years of education (primary)	21	13.8
	Between 5–10 years of education (secondary)	20	13.2
	>10 years and beyond (college)	8	5.3
	Still in education	17	11.2
	NA (infant)	1	0.65
Financial status	Earners (in a paying work/job)	62	40.8
	Non-earners	90	59.2

NA = not applicable.

using the PMDT services, and the financial impact of seeking PMDT services.

Accessing the PMDT clinic

The majority of patients (126/152, 83%) were able to manage a round trip to the PMDT clinic in a single day, while respectively 23/152 (15.1%) and 3/152 (2.0%) had to stay overnight in a hotel or at a relative's house to attend the clinic. The median roundtrip time was 4.0 h (range: <1–16) for day travellers, while it was 13.5 h (range: 6–72) in case of overnight stays. Regarding the mode of travel, 123/152 (81%) patients generally travelled to the clinic by public transport, 15/152 (9.8%) had to hire a vehicle, while 14/152 (9.2%) owned a motorbike or car which was used to reach the clinic. Travel costs, calculated for the patient and the accompanying persons for their most recent visit to the PMDT clinic, were substantially higher for patients staying overnight compared to those requiring a day trip only (Table 2).

The majority of patients (136/152, 89.5%) attended the PMDT clinic regularly, i.e., every month, to receive health services and collect their DR-TB medicines, while 6/152 (4%) were irregular in their visits, often sending a relative to collect medicines on their behalf. Another 10/152 (6.5%) patients never attended the clinic after initial registration, and a family member instead of the patient used to collect the patient's medicines from the clinic. Of 136 patients attending PMDT clinic regularly, 92/136 (67.6%) were always accompanied by at least one family member (range: 1–4), 29/136 (21.4%) always visited the PMDT clinic alone, while 15/136 (11.0%) sometimes attended alone and at other times were accompanied by a family member.

Using the PMDT package of health services

The median consultation time with the PMDT healthcare team during the patients' most recent visit to the PMDT clinic was 10 min (range: 2–20). In Site 1, the median consultation time was 10 min (range: 2–20); in Site 2, this was 15 min (range: 10–20); and in Site 3, this was 5 min (range: 2–20). During these consultations, patients were regularly referred for a range of laboratory and other tests (such as chest X-rays) to assess their treatment response and monitor drug side effects. The median waiting time in the tertiary hospital laboratories was 2 h (range: <1–3.5). Due to the non-availability of a number of tests in the hospital laboratory, 68/152 (44.7%) of patients during their most recent visit had to spend out of pocket (OOP) to obtain tests from private laboratories. The median OOP payment for these tests was PKR375 (range: PKR100–4000). Similarly, although the DR-TB medicines were free, 108/152 (71%) of patients incurred OOP expenses for ancillary medicines (to manage the side effects of the DR-TB drugs) in their most recent visit to a PMDT clinic. The median OOP payment made to buy these medicines was PKR300 (range: PKR80–1300).

Given the importance of the role of the treatment supporter in the PMDT model, a number of questions in the survey were related to their involvement in patient care. We found that no treatment supporter had been nominated for 15/152 (10%) of patients, although these patients had received treatment for 2–30 months. Of the remaining 137 patients with an identified treatment supporter, 60 (43.7%) accompanied the patient to the PMDT clinic regularly, i.e., every month. The remaining patients were either accompanied by someone else or visited the clinic alone. Only 8/137 (6%) treatment supporters supervised patients' daily intake of oral medicines at home. In the rest of the cases, the daily oral dose was either self-administered or given by someone else in the family. Similarly, the financial support mandated by the PMDT policy was received irregularly by 98.6% patients; many patients reported receiving the payment after a gap of many months. A high number (62/152, 40.7%) of patients reported never receiving any financial support despite being on treatment for an average of 7 months. None of the patients possessed any other health insurance and all disease-related costs, if not provided for by the PMDT model, were personally borne by patients and their families.

The contribution of public health facilities such as BMUs to DR-TB patient care was assessed in the context of daily injection

TABLE 2 Travel costs (including spending on food and accommodation) associated with accessing care at PMDT clinics*

	Day trip			Overnight stay		
Category of costs	Mean PKR	Median PKR	Range PKR	Mean PKR	Median PKR	Range PKR
Travel	718	475	40–8000	1875	1500	330–6000
Food	193	120	0–1000	800	575	100–3000
Accommodation	0	0	0	491	400	200–900
Total spending	911 ($6.5)	645 ($4.6)	40–9000 ($0.28–64.7)	3110 ($22.3)	2775 ($20)	930–7700 ($6.6–55.3)

*US$1 = PKR139 in 2018–2019.
PMDT = programmatic management of drug-resistant TB; PKR = Pakistani rupee.

administration. Of 129 patients on treatment regimen that included injections, only eight (6.2%) patients received/were receiving their daily injections from nearby public health facilities. There were 110 (85.3%) patients who received injections from either private practitioners, pharmacists, relatives, friends or neighbours, while 11 (8.5%) patients received injections from multiple sources.

Financial impact

Table 3 presents the financial status of patients at the time of the interview. In Table 3, the non-earner category included housewives, minors, students and men unable to work due to ill health and therefore financially dependent on their families. Earners included small business owners, skilled/unskilled labourers, crop/cattle farmers, retirees on pension and professionals such as technicians and teachers. Among the earners who stopped working entirely after initiation of DR-TB treatment, the majority (55%) were labourers and farmers. Of those who continued working, their median work hours decreased from 8 to 5 h per day.

Patients were asked about their average household income per month. Of 152 survey respondents, 29 (19%) were not aware of the monthly household income. The median household income of the remaining 123/152 (81.0%) patients was PKR12,000 (US$86.3). Among these, 31/123 (25.2%) households had zero income and were dependent on neighbours or humanitarian organisations for support. Nearly half of the households (60/123, 48.8%) reported a monthly income of PKR 1,500–15,000 (US$10.7–108); 27/123 (22.0%) had an income of PKR >15,000–35,000 (US$108–251.7); and 5/123 (4.0%) of patients had an income of PKR>35,000–100,000 (US$251.7–719).

To assess the extent of financial hardship borne by patients seeking healthcare for DR-TB, we calculated the amount spent by each patient at their last visit to a PMDT clinic, including travel costs (transport, food and accommodation) and spending on services not available in the tertiary hospital (tests from a private laboratory and ancillary medicines), and used the self-reported monthly household income as the denominator. Of the 123 patients for whom the last month's household income was known, 43 (34.9%) patients spent >40% of their income on costs associated with accessing treatment from the PMDT clinic in the last 1 month (Table 4).

To cover expenses during their current course of treatment, 109/152 (72%) patients borrowed money. The median amount borrowed was PKR35,000 (US$251.7). The money was borrowed in almost all instances from friends, family or neighbours; and patients were typically expected to return the amount (with no interest), whereas 55/152 (36%) patients reported selling assets to meet their expenses. Items sold included cattle, motorcycles, gold, mobile phones and other household items. In almost all instances, the amount received when selling assets was considerably less than the purchase cost. Two thirds (100/152, 65.8%) of patients felt they were becoming financially more impoverished as a consequence of DR-TB and the subsequent treatment, while 52/152 (34.2%) considered their financial condition unchanged.

TABLE 3 Financial status of patients (n = 152)

Financial status	*n/N*	%
Non-earners	90	59.2
Earners	62	40.7
Working in formal sector (e.g., teacher, technician)	10/62	16
Working in informal sector (e.g., labourer, farmer)	52/62	84
Primary breadwinner among earners	45/62	72
Earners who stopped working after treatment initiation	32/62	51

TABLE 4 Extent of financial hardship borne by patients (n = 123)

Proportion of the last month's income spent for seeking healthcare from a PMDT clinic %	Patients	
	n	%
⩽10	34	27.6
>10–20	28	22.8
>20–40	18	14.7
>40	43	34.9

PMDT = programmatic management of drug-resistant TB.

DISCUSSION

In this section, we discuss the survey findings with a view to understanding them in the context of Pakistan; we signpost implications for the NTP and propose recommendations for improving the responsiveness of the DR-TB services.

In Pakistan, PMDT clinics were established at the district level to improve patients' geographic access to specialised care for DR-TB. However, given the size of the districts in KP Province, many patients still had to travel for hours, and some needed overnight stays to attend the PMDT clinic. To mitigate travel costs, a financial support scheme was established, but in practice patients reported receiving payments irregularly, or had not received any payments at all since the start of their treatment. Long travel distances and high travel costs are well recognised barriers to accessing care that can lead to delayed care-seeking and/or premature abandonment of treatment. Decentralisation of health services to village and community levels is often promoted as a way of enhancing people's access to health services.[15,16] In the case of Pakistan, the high number of non-functioning/under-utilised BMUs in villages makes this a less viable option.[17–19] Providing sufficient financial disbursements to patients on a regular and reliable basis can help to overcome the transportation and accommodation cost barriers experienced by many patients.

The standard operating procedures (SOPs) for PMDT clinics emphasise thorough clinical examination of patients, comprehensive counselling, systematic assessment of adherence to treatment and health education sessions to be conducted during patients' monthly visits.[6,8] We asked patients about their consultation time in PMDT clinics as a proxy measure of whether or not these services were being delivered as expected. The median time patients spent in the PMDT clinic was only 10 min, making it highly unlikely that the recommended health services were all delivered as recommended. A recent report on health systems in KP revealed that the average consultation time in public hospitals was 3.5–10 min. High patient-to-healthcare provider ratio was cited as the reason for the brevity of the consultations.[20] In comparison, the patient-provider ratios in PMDT clinics were relatively generous, with eight staff members appointed at each PMDT clinic serving a patient population of <200 across the three study sites;[12] thus, a sub-optimal patient-to-healthcare provider ratio is not the explanation for such brief consultations in PMDT clinics. The short consultation time in the relatively well-resourced PMDT clinics points towards either issues in how PMDT staff are interpreting the SOPs, or how the SOPs are being implemented – perhaps both; this warrants further exploration and appropriate correction.

Our findings further revealed that 10.5% patients attended the PMDT clinic irregularly or had not attended at all, and their medicines were being collected by relatives. We acknowledge that patients need support when they are faced with problems that prevent them from attending appointments such as bad weather or illness. Nonetheless, dispensing medicines to relatives without clinical assessment of patients is an unsatisfactory practice. DR-TB is a potentially life-threatening illness that requires close monitoring by a trained healthcare team on a regular basis. Likewise, treatment supporters appear to have been underutilised in the PMDT model of care. Very few treatment supporters supervised the patient's daily intake of medicines or accompanied them to the clinic. An evaluation of the treatment supporter role, how it is understood by stakeholders, and how it is implemented in practice, and why, needs to be explored, understood and appropriately addressed.

In the PMDT model, it was assumed that laboratories at tertiary hospitals would be equipped to perform the tests needed for the management of patients with DR-TB, and the hospital would provide the ancillary medicines to patients with DR-TB through their essential drug inventory.[6,13] However, the public health system in Pakistan is deficient in many areas, including laboratory services and provision of essential medicines.[19–21] Our findings also reflect this gap — a high number of participants reported paying OOP for many ancillary medicines and other tests. These deficiencies in the public health system undermine the benefits of establishing PMDT clinics in public tertiary hospitals and highlight larger health system gaps in Pakistan.

In this survey, the role of the village/community-level health facilities in providing health services to patients with DR-TB was explored only in the context of daily injection administration. Our results indicate that the vast majority of patients did not access these public health facilities at all. The frequent non-functioning of BMUs constitute yet another health system gap in Pakistan;[17] this contextual feature plausibly explains why patients had to seek alternative providers for their daily injections. Other reasons why people in Pakistan prefer not to use public health facilities include absenteeism and unresponsive attitudes of staff;[17,19,20] these reasons might also hold true for our study participants. These broader health system gaps in Pakistan present further barriers to effective implementation of the PMDT model of care.

We also examined the overall financial hardships that patients with DR-TB faced while on treatment at PMDT clinics. The median self-reported monthly household income of the participants was PKR12,000 (US$86.3), which is less than the median monthly household income in the lowest wealth quintile in Pakistan (PKR23,192; US$166.8).[22] Our results reaffirmed that TB/DR-TB is a disease of poverty and predominantly affects those who are already vulnerable and facing financial hardship.[23] That 34.9% of these (very poor) patients were having to spend >40% of their monthly income to remain on treatment highlights the extent of financial hardship many patients face as a consequence of illness and the related treatment. A more effectively delivered and monitored financial support package that ensures patients receive payments regularly as promised, and a partnership with health actors beyond the public health system for essential tests and ancillary medicines at negotiated/subsidised rates to be covered by the TB programme/partners would mitigate some of these financial constraints.

This study has limitations that should be considered. Due to time and budget constraints, we conducted this study in only three PMDT sites in one province in Pakistan. A large-scale survey across the country is suggested to better appreciate challenges faced by patients with DR-TB. Similarly, the economic impact of DR-TB was examined briefly, and data were collected based on a single interview per patient and self-reported income. Cost patterns may change over time during the course of treatment; thus, a longitudinal and focused costing survey can provide a more realistic picture of patients' financial constraints and is recommended for future studies. Finally, since the focus of the study was patients receiving health services from the PMDT model of care, healthcare experiences and financial hardships of patients with DR-TB outside the PMDT network were not captured and may be very different.

CONCLUSION

This study identified significant patient-reported differences between PMDT policy and practice, including very short consultation times, disbursement of DR-TB medicines to relatives without clinical assessment of patients, underutilisation of treatment supporters and irregularities in the disbursement of financial support. We also highlighted how gaps in the broader health system of Pakistan contributed to these programmatic shortcomings. Urgent attention is needed to review PMDT implementation and ensure that vulnerable patients receive health services and financial support as intended in the PMDT model of care.

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