Original research

SOCIAL SUPPORT PROGRAMME FOR TUBERCULOSIS PATIENTS IN ARMENIA: PERCEPTIONS OF PATIENTS AND DOCTORS

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ABSTRACT

Background and objective: Adherence to treatment is an important factor for the successful treatment of tuberculosis (TB). Many countries have introduced incentive mechanisms to enhance adherence. Armenia provides social support packages of food and hygiene kits to TB patients. We aimed to evaluate the importance of the social support programme among 500 randomly selected TB patients and their physicians.

Methods: We used a mixed-methods approach(both qualitative and quantitative) with a retrospective descriptive study design. For the qualitative part, 40 in-depth interviews were conducted with 20 TB patients and 20 TB physicians. For the quantitative study, medical records and face-to-face interviews with 500 randomly selected TB patients and their TB doctors served as the data sources.

Results: Out of 500 patients, 490 (98%) reported receiving social packages during treatment and 470 (96%) were satisfied (based on the patient's personal perception) with them. Most of the patients preferred monetary incentives (274 [57.8%]) instead of the currently provided food and hygiene kits. Treatment success was positively associated with satisfaction with the social support provided (odds ratio [OR]=2.8, 95% confidence interval [CI]: 1.0; 7.6, P=0.04), treatment interruptions that did not last longer than a week (OR=4.1, 95% CI: 2.4; 7.1, P<0.01) and having "regular" TB (OR=3.0, 95% CI: 1.7; 5.3, P<0.01).

Conclusion: More flexible social support packages that better address patient needs would enhance treatment adherence, which would result in better treatment outcomes and programme improvement.

Keywords: OPERATIONAL RESEARCH, TUBERCULOSIS, TB SOCIAL SUPPORT, TB TREATMENT ADHERENCE

INTRODUCTION

Tuberculosis (TB) is a serious public health problem in Armenia. The estimated prevalence of TB in 2013 was 66 per 100 000 population *(1, 2)*. Armenia is among the 27 countries with a high burden of multidrug-resistant (MDR)[a]/extensively drug-resistant (XDR)[b]-TB cases. The estimated proportion of MDR-TB in Armenia is 9.4% among primary TB cases and 43% among previously treated TB cases *(1, 2)*.The increasing prevalence of M/XDR-TB is of urgent concern *(2, 3)*.

One of the major challenges to TB control is ensuring the continuity of TB treatment, as treatment interruptions pose a serious risk for treatment failure and development of M/XDR-TB *(4, 5)*. To counter this, TB programmes in several countries provide incentives, such as financial and material support, to encourage adherence and increase the success rates of TB treatment *(4–7)*. Incentives could be in the form of direct payments, deposit accounts, and food or

[a] Defined as TB caused by strains of Mycobacterium tuberculosis that are resistant to at least isoniazid and rifampicin

[b] Defined as MDR-TB plus resistance to a fluoroquinolone and at least one second-line injectable agent: amikacin, kanamycin and/or capreomycin)

hygiene packages *(8–10)*. In Bangladesh, patients who were adherent to treatment earned money saved in deposit accounts, which was provided upon completion of treatment *(11)*.In Russia, provision of assistance packages brought down incomplete treatment rates from 15–20% in 1999 to 2–6% in 2004 *(12)*.

Continuous monitoring and evaluation of the effectiveness of such projects is important, as their impact might vary over time, and they may need to be revised. For instance, monitoring of the social support project in India showed that some patients wanted to extend the course of their treatment in order to receive monthly cash assistance for a longer period of time, but intentionally avoided taking medication. The programme duration was then revised and a maximum 6-month period of cash assistance was introduced *(13)*.

TB care in Armenia is provided by specialized TB doctors (phthisiatricians). Although TB services are completely free for Armenian citizens *(14, 15)*, since 2009, within the national TB control programme in Armenia, the Armenian Red Cross Society with financial support from the Global Fund to Fight AIDS, Tuberculosis and Malaria organized a social support programme for TB patients during their treatment *(14)*. The aim of the programme is to increase treatment adherence, minimize treatment interruptions, and improve TB treatment outcomes.

We aimed to evaluate whether the social support programme for TB patients served as a tool for improving the adherence level of TB patients in Armenia, and offer suggestions for further programme improvement.

METHODS

STUDY DESIGN

This was a retrospective, non-interventional, non-controlled, randomized, descriptive study. We utilized a mixed-methods approach involving both patients and health-care providers, who participated in a qualitative study (in-depth interviews) and a quantitative survey (face-to-face interviews).

STUDY POPULATION

For the qualitative study, in-depth interviews were conducted with 20 randomly selected TB patients who had completed treatment, registered in 2013 and 20 randomly selected TB physicians.

The target population (*N*=1615) for the quantitative study included 1457 (90%) drug-susceptible (pan-susceptible) and 158 (10%) drug-resistant registered TB patients whose treatment outcomes were reported from July 2012 to June 2013. Of these patients, 500 (417 with drug-susceptible and 83 with drug-resistant TB) participated in the study (30%).

DATA COLLECTION AND SOURCES

For the qualitative survey, a semi-structured in-depth interview guide (Appendix 1) was developed, pre-tested and revised accordingly. It aimed to identify the knowledge and perceptions of the TB social support programme among TB patients and physicians. It contained 11 open-ended questions for TB patients and 7 for TB physicians. All the in-depth interviews were recorded, coded, and merged into categories and themes according to concepts and issues that the respondents emphasized.

The quantitative survey questionnaire was developed, pretested and modified to address the study objectives. It included data on demographic characteristics, satisfaction from social support packages, preferences regarding the type of packages, and possible reasons for treatment interruption. Face-to-face interviews were also conducted with 500 randomly selected patients from a list of all patients registered in Armenia during the study period as well as their TB doctors. Medical data on disease type and treatment outcome were extracted from the national TB electronic database.

DATA MANAGEMENT / DATA ENTRY

Data collection was based on abstraction of medical records and survey instruments. Electronic forms were developed using the Epidata software. Double data entry was carried out.

ETHICS

The study was approved by the Institutional Review Board / Committee on Human Research within the College of Health Sciences at the American University of Armenia. Before the interviews, permission to contact the patients was received from their TB doctors.

A consent form was read out to participants before the survey, which included information about the nature of the research, the risks and benefits of being included, and that participation was voluntary. Participants provided oral consent.

STATISTICAL METHODS/ANALYSIS

The analysis was preformed using STATA 10 statistical software. After conducting basic descriptive statistics (means, medians, standard deviations, frequencies), the differences between groups were assessed using the chi-square/Fisher exact test for categorical variables and the student *t*-test for continuous variables.

RESULTS

QUALITATIVE STUDY AMONG TB PATIENTS

Twenty randomly selected TB patients (10 men and 10 women) who had already completed treatment participated in the interview. The themes were mainly concentrated on their awareness of the disease, the challenges they faced during treatment, and any needs that could be addressed for better adherence. Concerning the nature of the disease, interviewees mainly described it as an infectious disease that requires long-term treatment, which they came to know about only during the course of their treatment.

Many of the respondents indicated that the disease affected their work. This was a serious problem, more so for those with jobs that demanded intense physical activity. Because of the inability to continue working during treatment, some of the patients had to stop working, which worsened their family`s socioeconomic conditions.

Patients reported that communication with their friends and relatives suffered during the course of treatment, mainly because they tried to prevent infecting others. Despite limitations in communication and socializing, patients did not feel that they were stigmatized or discriminated against by family and friends.

Almost all respondents indicated that the physicians provided free care; nonetheless, they needed additional financial support, particularly during the winter season.

Patients' preferences about the ongoing social support programme differed in terms of the type of support. Some preferred food packages, saying that even if they had received money they would have spent it on food. However, some mentioned that they would like to receive monetary assistance instead of the current food packages, because they could then decide what to spend the money on. Despite the differences in preferences, all of the respondents expressed great satisfaction with the social support programme and highlighted its importance.

Patients indicated that a variety of often correlated factors influenced completion of their treatment course. Among these factors were the awareness of the importance of treatment, a favourable attitude toward the treatment outcome, good family support, a good attitude of health-care providers, and the distribution of social support packages. Another factor mentioned by TB patients was the distance they had to travel to access the TB outpatient services. Moreover, the need for regular attendance at TB outpatient services resulted in missed working hours for some patients.

QUALITATIVE STUDY AMONG TB PHYSICIANS

According to the 20 randomly selected TB physicians, the disease had a significant impact on patients' socioeconomic condition. Health-care providers generally described their patients as being "isolated from the surroundings" and as"feeling humiliated". Nonetheless, after a discussion and educational training of patients and their families,[c] they became more comfortable and could better cope with the psychological challenges of TB. According to health-care providers, the employment status of patients was also affected. As most of the patients had a low socioeconomic status, financial problems became the main challenge during the treatment period, and the social support packages were thus of considerable importance. They mentioned that several patients came to get the treatment only to receive the social support packages. Health-care providers also mentioned that monetary support might introduce a risk, as many patients may spend the money on non-essential and sometimes even harmful things such

[c] Educational campaigns for TB patients and their family members are provided during the outpatient phase of the treatment by social workers of the Armenian Red Cross within the ambit of the NTP.

as alcohol and cigarettes. Besides, during the winter season, electricity and gas bills could also be a huge burden for TB patients and their families, so it would be beneficial for some patients to receive assistance for heating their houses. All respondents believed that the social support programme had a significant, positive impact on patients' adherence to treatment. The social support programme was also good for patients' families. As many patients were not able to work, they could contribute to decreasing the family burden by giving the social support package to their families. The physicians also reported that another benefit of the social support programme was that family members became more supportive of the patient. Specific recommendations to increase the effectiveness of the social packages were to diversify the foods provided and make the social support packages more comprehensive. A few health-care providers suggested giving coupons to patients so they could buy food and other products (excluding alcohol and tobacco) from specific stores.

QUANTITATIVE SURVEY

Overall, 30% (500/1615) of the TB patients from the target population participated in the study. The TB doctors of the study participants were also interviewed. The most common cause of treatment interruptions among patients with a history of interruption was the side-effects of treatment, which were mentioned by 165/328 patients (50.8%). The most preferred type of social support was monetary support, according to the TB patients (57.8% [274/483]) as well as TB physicians (84.7% [409/483]). Other causes of treatment interruption and preferred types of social support are presented in Tables 1 and 2.

The socioeconomic and clinical characteristics of the sample and their association with treatment outcome are presented in Table 3. According to the study results, the main outcomes observed were the following: 85 patients (17%) were cured, 338 (67.6%) completed treatment, 8 (1.6%) failed treatment, 32 (6.4%) defaulted and 37 (7.4%) were transferred out. A successful treatment outcome was defined as "treatment completed" or "cured" (overall 84.6%) and an unsuccessful treatment outcome was defined as any outcome other than a successful one.

Out of all 500 patients, 490/500 (98%) needed and received social support, according to the TB physicians. Only about 7/500 (1.4%) of the patients refused the social support; however, this was not associated with the treatment outcome.

According to the physicians, the social support packages were an additional incentive for 88.2% (435/500) of the patients. Evaluation of the satisfaction from TB services and social support packages was based on the patient's personal perception. Analyses showed that patients who were in general satisfied with the social support packages had a better chance of a successful outcome (odds ratio [OR]=2.8, 95% confidence interval [CI]: 1.0; 7.6, P=0.04). In addition, patients for whom the social support was important were more likely to have a successful outcome (OR=2.1, 95% CI: 1.1; 4.0, P=0.02), as were those whose treatment was not interrupted for more than a week (OR=4.1, 95% CI: 2.4; 7.1, P<0.01).Women were 2.7 times more likely to have a successful outcome than men (OR=2.7, 95% CI: 1.3; 5.7, P<0.01).Similarly, those receiving social support packages throughout their treatment had

TABLE 1. REASONS FOR TREATMENT INTERRUPTION ACCORDING TO TB PATIENTS

Variables	N (%)
Total number of patients with any treatment interruptions	N=328
The reasons mentioned for the interruption	
Treatment side-effects	165 (50.3%)
Long duration of treatment	20 (6.1%)
Migration for work	14 (4.3%)
Medications not provided to be taken home	9 (2.7%)
Treatment interfered with the job	8 (2.4%)
Feeling good	8 (2.4%)
Not trusting health-care providers	2 (0.6%)
Being dissatisfied with health-care provider's behaviour	2 (0.6%)
Did not want others to know about my disease	3 (0.9%)
Problems with transportation	3 (0.9%)
I don't know	68 (20.7%)
Other	26 (7.9%)

TABLE 2. PREFERRED TYPE OF SOCIAL SUPPORT ACCORDING TO TB PATIENTS AND TB PHYSICIANS

	According to TB patients	According to TB physicians
Total number of patients	N=483	N=483
Cash/monetary support	274 (57.8%)	409 (84.7%)
Food packages	114 (24.1%)	70 (14.5%)
Hygiene packages	1 (0.2%)	1 (0.2%)
Fruit and juice	5 (1.1%)	0 (0%)
Transportation costs	0 (0%)	2 (0.4%)
Assistance with heating bills	11 (2.3%)	1 (0.2%)
Other	69 (14.6%)	0 (0%)

TABLE 3. TB TREATMENT OUTCOME AND POTENTIALLY ASSOCIATED CHARACTERISTICS

Characteristics	Total (N, %) 500 (100%)	Unsuccessful treatment outcome (N, %) 77 (15.4)	Successful treatment outcome (N, %) 423 (84.6)	Unadjusted OR	95% CI	P-value
Sociodemographic						
Male Female	378 (75.6) 122 (24.4)	68 (88.3) 9 (11.7)	310(73.3) 113(26.7)	2.7	(1.3; 5.7]	<0.01[a]
Age *(mean ± SD)*	42.0 ± 15.9	40.5 ± 14.6	42.2 ± 16.1	1.7 ± 1.8	(-5.6; 2.1)	0.4[b]
Age ≤40 years Age >40 years	223 (44.7) 276 (55.3)	38 (49.3) 39 (50.7)	237 (43.8) 39 (56.2)	1.2	(0.8; 2.0)	0.4[a]
Rural residence Urban	145 (29.1) 354 (70.9)	19 (24.7) 58 (75.3)	126 (29.7) 296 (70.1)	0.8	(0.4; 1.3)	0.4[a]
Received social support Did not receive social support	490 (98.0) 10 (2.0)	75 (97.4) 2 (2.6)	415 (98.1) 8 (1.9)	0.7	(0.2; 3.5)	0.7[c]
Did not refuse social support Refused social support	493 (98.6) 7 (1.4)	76 (98.7) 1 (1.3)	417 (98.6) 6 (1.4)	1.1	(0.1; 9.2)	1.0[c]
Social support was NOT an incentive for the patient, according to their TB physicians Social support was an incentive for the patient, according to their TB physicians	58 (11.8) 435 (88.2)	10 (13.3) 65 (86.7)	48 (11.5) 370 (88.5)	1.2	(0.6; 2.5)	0.65[a]
Alcohol abuse, according to TB physicians NO alcohol abuse, according to TB physicians	34 (7.0) 448 (93.0)	7 (9.9) 64 (90.1)	27 (6.6) 384 (93.4)	1.6	(0.7; 3.7]	0.3[a]
It was easy to visit the TB cabinet It was difficult to visit the TB cabinet	228 (46.8) 259 (53.2)	36 (48.7) 38 (51.3)	192 (46.5) 221 (53.5)	1.0	(07; 1.8)	0.7[a]
Married Not married	368 (74.9) 123 (25.1)	57 (74.0) 20 (25.8)	311 (75.1) 103 (24.9)	0.9	(0.5; 1.6)	0.8[a]
School education College or higher education	372 (75.1) 123 (24.9)	60 (77.9) 17 (22.1)	312 (74.6) 106 (25.4)	1.2	(0.7; 2.1)	0.5[a]
Clinical						
Pulmonary TB Extrapulmonary TB	399 (79.8) 101 (20.2)	72 (93.5) 5 (6.5)	327 (77.3) 96 (22.7)	4.2	(1.7; 10.8]	<0.01[a]
Drug-resistant TB Regular TB	83 (16.6) 417 (83.4)	25 (32.5) 52 (67.5)	58 (13.7) 365 (86.3)	3.0	(1.7; 5.3]	<0.01[a]
New TB cases Retreated TB cases	347 (69.4) 153 (30.6)	54 (70.1) 23 (29.9)	293 (69.3) 130 (30.7)	1.0	(0.6; 1.8]	0.9[a]
Smear-positive TB Smear-negative TB	176 (35.2) 324 (64.8)	45 (58.4) 32 (41.6)	131 (31.0) 292 (69.0)	3.1	(1.9; 5.2]	<0.01[a]†
Not satisfied with social support provided Satisfied with social support provided	19 (3.9) 470 (96.1)	6 (8.2) 67 (91.8)	13 (3.1) 403 (96.9)	2.8	(1.0; 7.6]	0.04[a]
Social support is NOT important for the treatment, according to the patient Social support is important for the treatment, according to the patient	63 (22.7) 431 (87.3)	16 (21.0) 60 (79.0)	47 (11.2) 371 (88.8)	2.1	(1.1; 4.0]	0.02[a]
Interruption of treatment for more than a week Nointerruption of treatment for more than a week	80 (16.3) 411 (83.7)	28 (36.8) 48 (63.2)	52 (12.5) 52 (87.5)	4.1	(2.4; 7.1]	<0.01[a]
Provision of social support package terminatedbecause of interruptions Receivedsocial support packages throughout the treatment	36 (7.4) 453 (92.6)	11 (14.5) 65 (85.5)	25 (6.1) 388 (93.9)	2.5	(1.2; 5.6]	0.01[a]

[a] Chi^2 test
[b] Two-sample t-test
[c] Fisher exact test

a higher likelihood of a successful outcome (OR=2.5, 95% CI: 1.2; 5.6, *P*=0.01). Extrapulmonary TB (OR=4.2, 95% CI: 1.7; 10.8, *P*<0.01), regular (drug-susceptible) TB (OR=3.0, 95% CI: 1.7; 5.3, *P*<0.01) and smear-negative status (OR=3.1, 95% CI: 1.9; 5.2, *P*<0.01) were positively associated with successful treatment outcomes.

DISCUSSION

Our study aimed to evaluate the perceptions of TB patients and their doctors regarding the social support programme provided to TB patients in Armenia. One of the strengths of this study was that it combined both qualitative and quantitative findings. This approach provided a better understanding of the social support programme. We included not only patients' perspectives but also those of health-care providers,which provided different views on the same issue.

Adjustments to the quantitative survey instrument were based on the qualitative part of the research and pretested before use. Analysis of the findings from the quantitative survey showed that about 98% of respondents needed the social support packages and about 25% of them decided to continue their treatment due to these packages. Provision of these packages also served as an incentive for about 88% of patients to adhere to their treatment regimen.

We found that the majority of health-care providers and patients would prefer monetary support instead of the currently provided food and hygiene kits; however, some physicians raised the concern that patients might spend their money on alcohol and other unnecessary products. According to health-care providers, monetary support would be beneficial, particularly for those patients who are not alcoholic.

The outcome of treatment was successful in 84.6% of the patients, which is higher than the treatment success rate of the national cohort, because in the sample,"death" was not included as an outcome, which is a limitation of the study. Treatment outcome was associated with a variety of factors, including treatment interruptions lasting for more than a week, gender, and the type of TB (pulmonary or extrapulmonary).

Termination of social support because of interruptions in treatment was also adversely related to treatment outcomes, implying that sometimes the social support provided is not enough for keeping patients adherent to the treatment.

Satisfaction with the provision of social support was related to successful treatment outcome, suggesting that those with successful treatment outcomes were highly satisfied with the TB services.

Our study had some limitations. Although the provision of social support had a significant positive impact, it was not possible to evaluate the adjusted and causal impact of the social support programme on the success rate of TB treatment, as multiple factors influence adherence. Because of the retrospective design of the study, another limitation could be a recall bias. In addition, we could not collect all sociodemographic and clinical characteristics of interest, such as the availability of drug-susceptibility testing and its results.

The results of our operational research, which was carried out within the national TB control programme (NTP) of Armenia, were used to further improve the social support project. In 2015, the Armenian NTP introduced a new model for providing social support. Within this new model, the NTP will provide monetary incentives to patients, as it was the most preferred type of incentive, according to the study results. However, an individualized approach will be used. For example, the NTP could directly provide money for utility bills or for some other type of expenses presented by TB patients. Such flexibility in and opportunity for making choices can result in improved effectiveness of the project. For instance, some patients, especially those living in villages, grow their own food; therefore, the current food packages are not useful for them. Instead, if they get money, they are able to purchase other necessities. This approach will also save on transportation costs incurred in order to deliver the social support packages to TB patients. On the other hand, among patients with a higher socioeconomic status, the social support packages may not be as powerful of an incentive for treatment adherence as compared to those with a low socioeconomic status. Thus, adherence to treatment among TB patients could be further improved by targeting patients' needs. This approach will make social support packages more effective. Such programmes can be implemented in countries with a similar socioeconomic and health profile.

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APPENDIX 1. QUALITATIVE SURVEY: SEMI-STRUCTURED IN-DEPTH INTERVIEW QUESTIONS FOR PATIENTS AND PHYSICIANS

QUESTIONS FOR TB PATIENTS

1. What do you know about tuberculosis?
2. How is tuberculosis cured/treated?
3. Do not read, if the patient does not mention anything, ask: /medications /nutrition/hygiene, etc.
4. How does the presence of tuberculosis affect your working function/capacity?
5. How does the presence of tuberculosis affect your financial status?
6. How does the presence of tuberculosis affect the relationships with your acquaintances and friends?
7. How can the Ministry of Health/other organizations help you to cope with the disease and get treatment?
8. Which type of social support is more preferable to you (packages/financial reimbursement/other) and why?
9. What is your opinion about the social support programme?
10. What are the factors contributing to the completion of treatment?
11. What are the factors contributing to the completion of TB treatment, which are not considered within the scope of the programme?

QUESTIONS FOR TB PHYSICIANS

1. How does the presence of tuberculosis affect the socioeconomic activity of the patients? (communication with friends, work, etc.)
2. Which type of social support is preferable to the patients – packages/financial reimbursement/other?
3. How does the social support programme affect the treatment adherence of patients?
4. How does the social support programme contribute to the patient care provided by family members?
5. What is your opinion about the social support programme?
6. What are your suggestions for further programme improvement?
7. What are the factors affecting treatment adherence that should be considered in the future?