



USAID
FROM THE AMERICAN PEOPLE

TB CARE I

TB CARE II

Lessons Learned from Best Practices in Psycho-Socio-Economic Support for Tuberculosis Patients

Susan van den Hof¹, David Collins², Ieva Leimane¹,
Ernesto Jaramillo³, Agnes Gebhard¹

¹ KNCV Tuberculosis Foundation

² Management Sciences for Health

³ World Health Organization

November 2014



Table of Contents

Acknowledgments	
Abbreviations	
Executive Summary.....	1
Background	3
Collection of Best Practice Information	5
Case Studies	7
Involving expert patient trainers in the Programmatic Management of TB (PMDT) communication training for health workers in Indonesia	8
National scale up of social support in Kazakhstan	11
Governmental social support in Riga, Latvia.....	15
Social support for MDR-TB patients in Namibia.....	17
Fund for Special Needs in The Netherlands	20
Patient-Centered Approach Package.....	22
Social support for MDR-TB patients in Peru.....	25
Patient-Centered Accompaniment in Voronezh, Russia	28
Social support for MDR-TB patients in Rwanda	31
Social Support to Strengthen Outpatient Care in Tajikistan	33
Key Findings.....	35
Lessons Learned	37
Conclusions and Recommendations	38
Annexes.....	41
1. Best Practice Data Collection Questionnaire.....	41
2. Contact Details Per Initiative	46
References	47

Acknowledgments

This report on 'Best Practice in Psycho-Socio-Economic Support for Tuberculosis Patients' would not have been achieved without the involvement and support of a significant number of stakeholders, namely National TB programs and TB CARE I/TB CARE II coalition member organizations. We appreciate them taking the time to participate and provide the information that formed the basis of this report.

The Global Health Bureau, Office of Health, Infectious Disease and Nutrition (HIDN), US Agency for International Development, financially supports this publication through TB CARE I under the terms of Agreement No. AID-OAA-A-10-00020. This publication is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of TB CARE I and do not necessarily reflect the views of USAID or the United States Government.

Abbreviations

ATS	American Thoracic Society
FHI 360	Formerly Family Health International
JATA	Japan Anti Tuberculosis Association
MDR-TB	Multi drug resistant tuberculosis
MoH	Ministry of Health
NTP	National TB program
PCA	Patient-Centered Approach
PHC	Primary Healthcare Center
PMDT	Programmatic Management of Drug Resistant TB
TB	Tuberculosis
TB CARE (I and II)	USAID funded global projects (I and II) to fight tuberculosis
USAID	United States Agency for International Development
WHO	World Health Organization

Executive Summary

Tuberculosis (TB) patients face many psychological, social and economic problems that complicate treatment and care. This may lead to decreasing adherence to prescribed treatment regimens and poorer clinical outcomes, including higher loss-to-follow-up, relapse and mortality rates. Multi drug resistant (MDR) TB patients are at even higher risk of psychological, social and economic difficulties due to delays in the diagnosis of MDR-TB and the long duration of treatment after diagnosis. Worldwide treatment success among MDR-TB patients is only 50% with high rates of loss-to-follow-up.

Well-designed and effectively implemented programs that reduce or remove these psychological and socio-economic problems for TB and MDR-TB patients may improve individual health outcomes and programmatic indicators. These programs usually contain a mix of interventions ranging from patient information, counseling, psychological, social and financial support and sometimes donations in kind (the latter is also called enablers/incentives). In this report these are lumped together under the term "social" support, and where necessary a more precise term is used.

Knowledge about effective, evidence-based social support practices is crucial for care providers, NTP managers, donors and technical agencies that support TB programs. However, the processes and effects of social support interventions aimed at improving adherence of TB patients to treatment are rarely shared among National Tuberculosis Programs (NTPs) and care providers.

The aim of this project was to draw lessons from best practices on sustainable systems for social support from around the world, to learn what works in specific situations and can be adapted to similar problems in other contexts.

The social support interventions included in this project are intended to:

1. Enable and ensure adherence to TB and MDR-TB treatment;
2. Alleviate patient costs; and
3. Reduce the stigmatization of and discrimination against TB patients;

without using inordinate resources to achieve the desired results. An educational component is often embedded in these interventions though it was rarely the main objective.

In this project, we specifically looked at two components of social support, namely psycho-emotional support and socio-economic support. The latter includes both financial and material assistance aimed at helping TB patients to adhere to treatment. Social support interventions from both outpatient and inpatient models of care were included. Evidence of greater effectiveness and cost effectiveness for outpatient versus inpatient models of care has been generated elsewhere and is not addressed here.

DATA COLLECTION AND RESULTS

Questionnaires were sent to the TB CARE I partners (ATS, FHI 360, JATA, KNCV Tuberculosis Foundation, MSH, The Union and WHO) and to the TB CARE II project with the request to distribute these to their country teams and to their corresponding national TB programs. The questionnaire asked for information on existing social support models that the respondents considered to be best practices.

In total we received information on the ten best social support practices from and through different partners, the descriptions of which are summarized in this report.

The qualitative data suggest that the practices reported were effective in improving treatment outcomes and reducing loss-to-follow-up. Reducing patient costs during treatment was not an explicit goal of any of the reported interventions, limiting the capacity to draw conclusions on this particular topic.

LESSONS LEARNED FROM THE BEST PRACTICE SOCIAL SUPPORT PROGRAMS

Effectiveness: The best practices identified here strongly suggest that psycho-socio-economic support interventions can add significant value to TB control through improvements in treatment success rates and reductions in patient suffering. Several programs considered cash payments an effective tool to promote adherence. Delivery of social support to TB patients requires collaboration through multidisciplinary teams, quite often in close collaboration with or organized by, people outside of the NTP.

Clear procedures for the identification of patients' needs through patient-centered approaches are likely to help effective targeting of social support resources and promote accountability. Well-designed social support systems can be a viable and affordable alternative to the compulsory treatment of non-adherent patients, without the human rights violations and risk of TB transmission commonly associated with this method of treatment.

Sustainability: Recognition by health sector leaders of the difficulties faced by patients to adhere to treatment is paramount for the adoption of social support interventions. Fundamental to the adoption, high-performance and sustainability of social support interventions are the existence (or development) of conducive legal frameworks, including both psycho-emotional and socio-economic support components, and collaboration between the Ministry of Health (NTP) and those responsible for social protection schemes in other government sectors.

Possibility for scale-up: The best practices identified here show that social support interventions are feasible and scalable, even in low income countries. Political commitment was found to be essential for the nationwide scale-up of social support interventions: in countries where political commitment was generated and was translated into support for legal frameworks and budgets from government or combined government and donor sources, projects have shown to be scalable.

CONCLUSIONS AND RECOMMENDATIONS

Comprehensive psycho-socio-economic support interventions are effective and feasible in both high and low income settings.

NTPs and their partners are advised to embed all the elements of social support interventions into the legal framework and to integrate (partial) government funding of the interventions into the design right from the start.

Countries are encouraged to explore the use of conditional cash transfers and microfinance. These forms of social support may be an effective way to alleviate poverty amongst TB patients and people in general.

NTPs and their partners are recommended to perform more systematic data collection for psycho-socio-economic support to monitor implementation and evaluate effectiveness and efficiency and to enable further assessment of equity and scalability of the different approaches. Special attention should be paid to evaluation of the reduction of cost burden, which is an explicit element of the End TB strategy. This information is to be used to show accountability and increase political commitment.

The WHO Global TB program is advised to work with partners to make specific recommendations on the use of social support interventions for TB care and control; propose a mechanism and indicators for countries to manage and monitor implementation; and to promote research needed to improve the understanding of the role of social support in TB care and control and increase its impact.

The Stop TB Partnership is recommended to strongly advocate for donors, countries, researchers and technical partners to incorporate social support interventions into their respective agendas to address the catastrophic costs patients incur, and mitigate the stigma and discrimination suffered by patients.

The Global Fund and other major donors are recommended to promote the implementation of social support interventions through sustainable funding mechanisms.

Background

Whatever the causes of the psychological, social and economic problems TB patients face, they complicate the care and clinical management of these patients by negatively affecting their quality of life and inducing direct and indirect costs.^{1,2} These problems can lead to decreasing adherence to prescribed treatment regimens and poorer clinical outcomes, including higher loss-to-follow-up, relapse and mortality rates.

MDR-TB patients are at even higher risk of psychological, social and economic difficulties due to delays in the diagnosis of MDR-TB and the long duration of treatment (sometimes up to 24 months). The long duration of treatment, adverse drug reactions, stigma and financial burden of TB all contribute to non-adherence to treatment and unsuccessful treatment outcomes, with worldwide MDR-TB treatment success rates of only 50% and variable but high rates of loss-to-follow-up.³

Systematic reviews suggest that well-designed and effectively implemented programs that reduce or remove psycho-emotional and socio-economic problems may improve treatment adherence.^{4,5,6,7} The authors of this report were involved in a recent systematic review and meta-analysis which confirmed that psycho-social and socio-economic interventions were associated with higher treatment success rates and lower loss-to-follow-up rates (unpublished data; article submitted for publication).

The need for strong, sustainable and scalable social support mechanisms in MDR-TB treatment becomes more evident as countries scale up MDR-TB treatment, while shifting from hospital based (inpatient) to ambulatory (outpatient) models of care.

Shifting treatment from inpatient to outpatient services allows for the scaling up of MDR-TB treatment and allows patients to be treated closer to home - at a lower cost to both the health system and patients. Effective social support can help make this shift work and therefore contribute to cost savings which may provide the budget for the social support programs. Evidence of better effectiveness and cost effectiveness for outpatient versus inpatient models of care has been generated elsewhere^{8,9} and is not addressed here.

Social support programs usually contain a mix of interventions including patient information, counseling, psychological support, provision of social services, and financial and material support (the latter are also called enablers and incentives). In this report these are lumped together under the term "social" support¹⁰, but where necessary a more precise term is used.

Box 1. Definition of main components of social support assessed in this report¹¹

In this project, we specifically looked at two main components of social support:

- Psycho-emotional support, which includes emotional support through psychological interventions; and
- Socio-economic support, which includes tangible support through interventions delivering services, material goods and/or financial assistance.

Social support can be measured in terms of individual's perceived support or in terms of the tangible support delivered. An essential element and important challenge for the successful treatment of TB patients is the organization of the additional psychological, social and economic support that individual patients need to enable their adherence to TB treatment; contribute to

alleviate the costs patients incur while seeking health care and receiving care and treatment, and to cope with the negative effects of disease and treatment, including the stigmatization and discrimination often exerted on patients and relatives.

Communities and governments struggle to develop systems that are able to provide social support in a patient-centered, fair, effective and sustainable way. In many countries social support for (MDR) TB patients is not initiated by local communities or governments but organized in parallel systems by international donors, despite the availability of some forms of in-country social protection provided by governments. This makes the successful treatment and patients' improved quality of life dependent on outside funding. Contributions from the informal social support networks of the communities where patients live quite often go unrecognized, and rarely benefit from institutional support. Members of such networks are often poor themselves and some may struggle to contribute even small amounts.

Knowledge of effective, evidence-based social support practices is crucial for care providers, NTP managers, donors and technical agencies that support TB programs. However, the processes and effects of social support interventions aimed at improving adherence of TB patients to treatment are rarely shared among National Tuberculosis Programs (NTPs) and care providers

To address this need the TB CARE I project initiated the collection and analysis of best practices of systems for social support from around the world. This assessment aims to document what works in specific situations, as an example for other contexts.

The social support interventions included are intended to:

1. Enable and ensure adherence to TB/ MDR-TB treatment;
2. Alleviate patient costs; and
3. Reduce stigmatization and discrimination;

without using inordinate resources to achieve the desired results.

An educational component is often embedded in these interventions though they were rarely the main objective. Social support interventions from both outpatient and inpatient models of care were included.

Collection of Best Practice Information

The project group developed a questionnaire to collect descriptions of best practices. Box 2 provides the definitions of a best practice, and Box 3 gives an overview of the topics included in the questionnaire to collect information on best practices.

Box 2. Definitions of a “Best Practice” ^{12,13}

A “Best Practice” is commonly defined as a technique or methodology that, through experience and research, has proven reliably to lead to a desired result.¹² In the context of health programs and services, a practical definition of a “Best Practice” is knowledge about what works in specific situations and contexts, without using inordinate resources to achieve the desired results, and which can be used to develop and implement solutions adapted to similar health problems in other situations and contexts. Error! Bookmark not defined.

The use of the word “best” should not be considered in the superlative sense. In other words, the term “Best Practice” is not about “perfection”, the “gold standard” or only elements that have been shown to contribute towards making interventions work or successful. Results can be partial and may be related to only one or more components of the practice being considered. Documenting and applying lessons learned on what does not work and why it does not work is an integral part of “Best Practice” so that the same types of mistakes can be avoided by others. Error! Bookmark not defined.

Making knowledge of such actions widely available may prevent the repetition of mistakes and loss of valuable time. Thus, the main rationale for documenting and sharing “Best Practices” is to enable persons and organizations working in the health sector to avoid “re-inventing the wheel”; to “learn in order to improve performance”; to “avoid the mistakes of others”; and to stimulate the development of innovative local solutions to global problems. Error! Bookmark not defined.

Box 3: Main topics in the data collection tool used for description of best practices

1. Context and justification
2. Description of the implementation of the Best Practice:
 - a) Implementation of psycho-emotional support (if applicable)
 - b) Implementation of socio-economic support (if applicable)
 - c) Details of Best Practice activities
3. Description of the setting where the best practice was implemented
4. Details on ambulatory care
5. Financing of the practice
6. Results of the Practice – Outputs and Outcomes
7. Lessons Learned
8. Conclusion
9. Further information (if available).

The WHO/AFRO guide on documenting and sharing best practices, describes nine criteria for best practices. Error! Bookmark not defined. There is overlap with criteria from the WHO/EURO Compendium on best practices in the prevention, control and care for drug-resistant TB.¹⁴ Two additional criteria, equity and a possibility of scale-up, are included in this compendium and we added these to the list of evaluation criteria (Box 4).

Box 4: Criteria for evaluation of Best Practices

1. **Effectiveness:** This is a fundamental criterion implicit in the definition. The practice must work in practice and achieve results (that ideally have been well documented)
2. **Efficiency:** The proposed practice must produce results with a reasonable level of resources and time
3. **Relevance:** The proposed practice must address the priority health problems in the region
4. **Ethical soundness:** The practice must respect basic ethical principles for the practice of public health, psychological and social work
5. **Sustainability:** Implementable or able to be maintained over a long period of time (including policy decisions), ideally without massive injections of additional resources
6. **Potential for replication:** The proposed practice, as carried out, has the potential to be replicable elsewhere
7. **Involvement of partnerships:** The proposed practice must involve satisfactory collaboration between several stakeholders
8. **Community involvement:** The proposed practice must involve the participation of the affected communities
9. **Political commitment:** The proposed practice must have support from the relevant national or local authorities
10. **Equitable:** Addresses the needs of vulnerable populations in an equitable manner
11. **Possibility of scale-up:** Can be scaled-up to a larger population.

For this project, the discussion will concentrate on “*effectiveness*”, “*sustainability*” and the “*possibility of scale-up*” as the aim is to identify effective and scalable models of care.

The questionnaire (see Annex 1) was sent to TB CARE I partners (ATS, FHI 360, JATA, KNCV Tuberculosis Foundation, MSH, The Union and the WHO) and the TB CARE II project management unit with the request to distribute the tool within their organization and among their partner organizations, to collect information on social support models they considered to be best practices.

In total we received information on ten social support models. Contact details of those who provided the information are provided in Annex 2. The practices and descriptions of the social support interventions are summarized in this report.

Key findings based on a qualitative analysis of these case studies are presented at the end along with conclusions and recommendations.

Case Studies

In this chapter you will find summaries on the ten initiatives on the provision of social support:

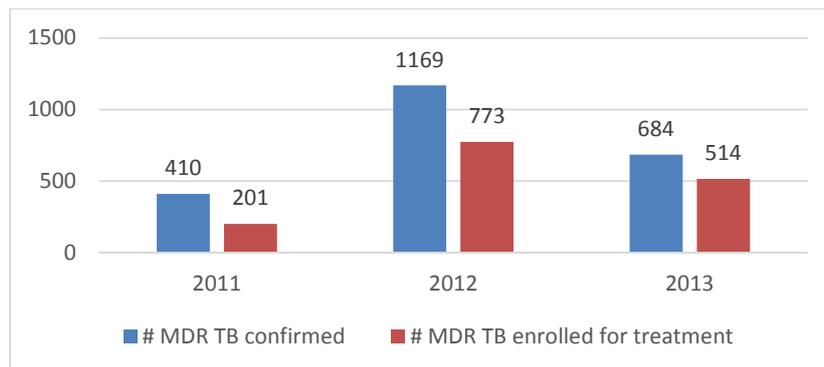
	Page
• Involving expert patient trainers in PMDT communication training for health workers in Indonesia	6
• National scale-up of social support in Kazakhstan	9
• Governmental social support in Riga, Latvia	13
• Social support for MDR-TB patients in Namibia	15
• Fund for Special Needs in The Netherlands	18
• Patient-Centered Approach Package in 5 countries (Cambodia, Indonesia, Mozambique, Nigeria and Zambia)	20
• Social support for MDR-TB patients in Peru	23
• Patient-Centered Accompaniment in Voronezh, Russia	26
• Social support for MDR-TB patients in Rwanda	29
• Social support to strengthen outpatient care in Tajikistan	31

Involving expert patient trainers in the Programmatic Management of TB (PMDT) communication training for health workers in Indonesia

BACKGROUND

In Indonesia, there are a high number of patients who are reluctant to access PMDT referral hospitals for the diagnosis of multi-drug resistant TB (MDR-TB). For those who are diagnosed with MDR-TB there is a low initiation rate of treatment regimens with second line drugs (SLDs) (Figure 1) which leads to ongoing morbidity and transmission in the community.

Figure 1. Number of MDR-TB patients diagnosed and enrolled for treatment in Indonesia, 2011-2013.



TREATMENT MODEL

MDR-TB treatment is provided on an outpatient basis. DOT is provided by nurses at all clinics.

OBJECTIVE OF THE EXPERT PATIENT TRAINER INITIATIVE

The objective of involving Expert Patient Trainers (EPTs) in PMDT communication training for health workers was to improve their communication skills and enable them to approach and motivate presumptive MDR-TB patients to seek diagnosis, and to help MDR-TB patients to accept their treatment plan and adhere to treatment.

PSYCHO-EMOTIONAL SUPPORT

MDR-TB patients who were cured or were in the continuation phase of MDR-TB treatment were trained as EPTs to give feedback on the communication skills of health care workers' (HCWs) in the PMDT Communication Training for HCWs.

The trainings began in March 2013 and were provided for doctors at PMDT services and nurses working in PMDT referral hospitals, sub-referral hospitals, treatment satellite units (including PMDT prisons satellite in DKI Jakarta & Central Java). Under this initiative two staff members were trained per facility.

During the Communication Training for HCWs, role plays were used involving EPTs: inmates, people living with HIV (PLHIV), people with presumptive MDR-TB and MDR-TB patients.

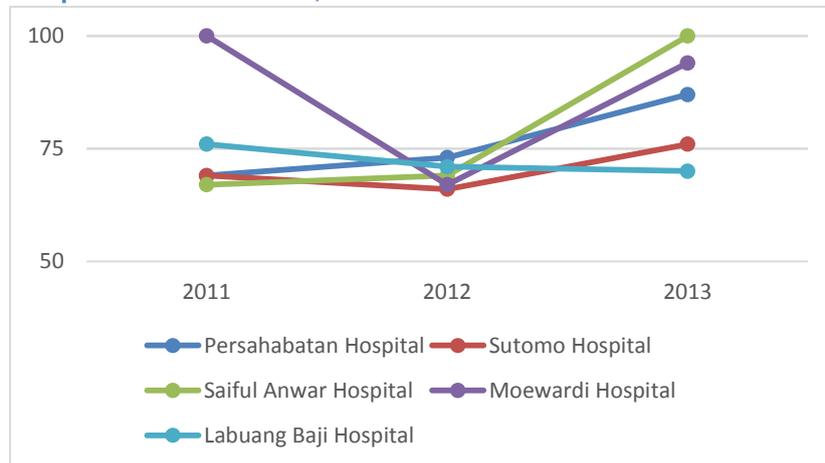
RESULTS

In 2013 the best practice was implemented in five PMDT referral Hospitals in four provinces (DKI Jakarta, Central Java, East Java and South Sulawesi), where 464 patients had received a confirmed diagnosis of MDR-TB, and 392 were enrolled for treatment.

Of the 72 patients who had not (yet) started second-line MDR-TB treatment, 12 patients refused to be treated and 28 could not be contacted. At the end of 2013, 37 patients were lost-to-follow-up for at least two months.

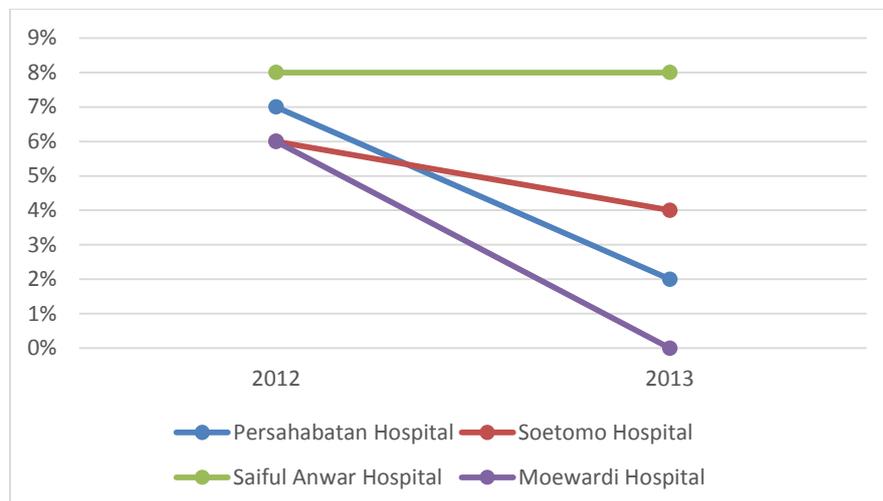
The number of MDR-TB patients in four out of the five PMDT referral Hospitals had increased compared to previous years (Figure 2).

Figure 2. Number of MDR-TB patients enrolled on treatment in five PMDT referral Hospitals in Indonesia, 2011-2013.



At the same time, the proportion of MDR-TB patients who refused to be enrolled on treatment in 2013 had not increased (and even decreased in three out of four hospitals with known data) in comparison with 2012 (Figure 3).

Figure 3. Proportion of patients refusing treatment in PMDT Referral hospitals in Indonesia, 2012-2013.



Note: 2011 data are not available, as refusal and loss-to-follow-up during treatment were not differentiated in that year.

Note: Data for Labuang Baji Hospital was not available.

To monitor the implementation of this practice, routine data for PMDT monitoring were used, therefore is not possible to say that all achievements were due to this best practice implementation. Practice outputs and outcomes were not systematically evaluated at the time.

FINANCING AND SUSTAINABILITY

The training curricula for EPTs was developed within the TB CARE I project (by the NTP, FHI 360, KNCV and the WHO), and the trainings were implemented through a Global Fund grant (training of HCWs).

The practice has not yet been scaled up beyond the original geographical area, due to current budget and trainer capacity.

BEST PRACTICES AND LESSONS LEARNED

- MDR-TB patients and former patients could be empowered to become EPTs and to provide feedback to HCWs on their communication skills, in order to improve health services and to motivate patients to complete their SLD treatment
- The NTP has accepted this method as standard policy and it will be integrated into National PMDT Training Modules on Patient Communication
- Due to the turnover (rotation) of HCWs involved in the treatment and counseling of MDR-TB patients, there is a need to expand the numbers of HCWs per facility being trained
- More Master Trainers should be trained so that it can be scaled-up
- Training follow-up needs to be implemented to monitor how many trained HCWs were actually implementing the new skills
- A monitoring and evaluation framework should be developed to measure the outcomes and impact of this best practice.

National scale up of social support in Kazakhstan

BACKGROUND

Kazakhstan has one of the highest prevalence rates of MDR-TB in the world: 20% among new patients, and over 50% among retreatment patients. **Error! Bookmark not defined.** Within the country, there are regions with an even higher prevalence of drug resistance, such as the East Kazakhstan and Akmola oblasts.

Most of MDR-TB patients come from vulnerable groups: the poor, homeless, ex-prisoners, PLHIV, drug/alcohol abusers and migrants. Currently, approximately 5% of patients discontinue MDR-TB treatment because of psychological and socio-economic barriers.

The Stop TB strategy based TB control program, has demonstrated success in curing TB patients. However, because of the complexity of some cases - especially among MDR-TB patients - it is necessary to strengthen the environment and support of the affected people in their various psychological (including stigma and discrimination in society) and social determinants (low-income, unemployment, transportation costs, bad nutrition, bad living conditions, drug and alcohol addiction, and delinquency).

TREATMENT MODEL

TB and MDR-TB patients in Kazakhstan are usually treated in hospitals for the majority of the intensive phase, then patients are treated as outpatients in ambulatory care facilities close to their homes.

In 2012 piloting of full outpatient care began in the Akmola oblast and MDR-TB patients could start SLD treatment in ambulatory settings from the first day of treatment or after a short period of hospitalization. The risk of loss-to-follow-up is considered to be highest during outpatient treatment.

OBJECTIVE OF SOCIAL SUPPORT

The objective of the social support program was to provide patient-centered psychosocial support to MDR-TB patients and their families in order to improve the treatment adherence rate. The prevention of catastrophic costs for patients was not an explicit objective.

PSYCHO-EMOTIONAL AND SOCIO-ECONOMIC SUPPORT

Beginning in 2010 in East Kazakhstan and 2013 in Akmola, intensified social support models were implemented through patient support groups consisting of a psychologist, a social worker and clinical staff.

The key elements of psycho-emotional support were:

- Advocacy work with local government and state budget holders to get strong commitment from TB programs and stakeholders for a patient-centered approach (PCA) and for the use of social packages
- TB patient support working groups were developed under local government and these assisted in the development of the model program for TB patients. These social groups consisted of psychologists, social workers, lawyers and TB nurses
- Psychosocial profiling was done by psychologists, and subsequently psychologists and other psycho-social support group members (TB nurses and social workers) under the supervision of the head of the TB unit, provided individual support for patients in three main areas: clinical care, psychological counseling (including importance of treatment adherence for the patient and their supporters) and the provision of socio-economic support
- The patient support group provided psychological counseling, treatment literacy, medication counseling and health education to the patients and their supporters.

Psycho-emotional support was provided throughout the whole course of treatment – during both the inpatient and outpatient stages of treatment. During the hospitalization period, group

counseling led by a psychologist or nurse was carried out weekly or upon a patients need or request. Participation in psychological counseling was voluntary, but the program tried to identify and counsel patients with emotional stability problems. It should be noted that during the first few months of implementation, many patients refused to have meetings with psychologists as they did not recognize that they really needed psychological support. But step by step the psychologists earned patients' trust and had meetings with them and their supporters.

The main psychological problems were related to the uncertainty of treatment success, stigmatization, lack of support and understanding within their environment, fear of losing current relationships, and a fear of not being able to marry in the future. Psychiatric patients were referred to specialists.

In addition, a program of socio-economic support is available for needy patients. Eligibility is based on a social profile of patients that identifies the main social risks of treatment interruption. As the risk of treatment interruption is biggest during outpatient treatment, the support mainly focuses on MDR-TB patients in the continuation phase of treatment.

Economic support was available from the relevant government social program and beyond that, patients were supported when necessary with conditional cash transfers based on correct adherence to treatment so that they could cover urgent domestic needs. Support could also be individual, such as nutritional supplements or assistance in creating a separate patient's room in the home.

Specifically patients had access to:

- State social disability allowance (Those in need are identified by social workers and signed off by the treating physician)
- Nutritional support in the form of a monthly basic food package (sometimes for families when patients are in hospital)
- A monthly basic hygiene package
- Help with documentation, interim housing and seeking jobs
- Free kindergarten.

RESULTS

In 2010, during the pilot implementation in East Kazakhstan 426 MDR-TB patients started SLD treatment. The psycho-social support program supported 228 (54%) patients considered to be at risk of treatment default. Out of those, 177 (78%) were considered to be in need of psycho-emotional support of whom 157 (89%) were provided with this support, and 213 (93%) were deemed to need socio-economic support of whom 175 (82%) received it. The main reasons why some patients who needed support, did not receive it, were that the two patient support groups could not cover all patients, especially those living in remote areas, and that some of the problems encountered by patients could not be solved by the patient support group, such as improving general living conditions. Many home visits were made; 195 were related to clinical care, 119 were to assess social status, and 63 were to provide psychological counseling for patients and/or their relatives.

The program contributed to strengthening the management of all MDR-TB patients during the ambulatory phase of treatment:

1. The proportion of drug doses taken under direct observation improved from 48% to 97%
2. Division of intake of SLDs in 2-3 portions per day decreased from 20% in 2009 to 0%
3. Interruptions of treatment for at least one day decreased from 18% to 4% among all MDR-TB patients. Among the patients included in the psycho-social support program, no treatment default was observed and only one patient missed doses of treatment.

In 2013, a similar patient support system was set up in parallel with the expansion of outpatient treatment in Akmola. So far, no patients put on full outpatient care were lost-to follow-up.

A more complete evaluation of the patient support models in East Kazakhstan and Akmola is ongoing.

FINANCING AND SUSTAINABILITY

Due to increased political support (as a result of the positive pilot results) and a greater understanding of the public health risks the local government has sharply increased funding for direct socio-economic support of TB patients and minimal support external donors is now required (The state financial contribution increased eight-fold for direct social support of MDR-TB patients in the East Kazakhstan and more than two-fold in Akmola). Additional funding is provided from the Global Fund grant for a small number of patients.

In Akmola, patient support is also provided from funds provided by the local government. Previous national policy documents made no mention of psycho-social support. However, in 2014 an order was approved which includes provision of psycho-social support to all (MDR) TB patients who needs support and risk interruption of treatment. This includes coverage of transport costs. Scale up of full outpatient care nationwide including provision of patient support is included in new National Strategic plan for 2014-2020.

LESSONS LEARNED AND BEST PRACTICES

The following lessons were learned:

- Strong political commitment was needed to pilot full outpatient care through the reduction of inpatient beds and a reallocation of savings for different kinds of outpatient care and direct social support of outpatients as well as the strong dedication and commitment of regional TB program staff
- Increased political commitment was achieved by evidence-based advocacy
- Group counseling built much better communication between patients and staff and also among patients themselves
- Advocacy was needed at all levels to overcome resistance from the Ministry of Health (MoH), NTP and Primary Healthcare Center (PHC) programs and to get political commitment and to establish the multidisciplinary working group to develop protocols and training materials, conduct training and lead supervision
- The MoH and NTP needed to recognize the success of the pilot of full outpatient care as a model for scale up in the country
- There is a need for a clear national TB policy which fits with national policies and practices.
- PHC services must be ready to provide outpatient care (provision of DOT during the intensive phase).

The following were considered by the respondent to be best practices:

- Establishing a TB patient support regional working group under the local government and assisting in the development of the patient support model program for TB patients
- Advocacy activities conducted through organizing set of round tables, regular meetings, study visits to learn best practices on patient support in different countries
- Establishing two multidisciplinary patient support groups consisting of psychologists, social workers and TB nurses based on developed clear job responsibilities and tasks division between patient support group members, reporting schemes, indicators, monitoring and supervision
- The involvement of ex-patients and local NGOs, despite the fact that civil society is weak in the country
- Training (basic and refresh) of patient support groups members and supervisors on interpersonal communications and counseling skills
- Recruiting professional social workers designated as a treatment support coordinators at the regional level (small fees were provided to reimburse transportation costs for home visits and other working visits to state bodies)

- Monitoring and supervision of patient support groups work by the project team and NTP supervisors
- Discussions of interim results, lessons learned, challenges and further steps during the project; this assisted in making an evidence-based case on the pilot results and thereby enhancing political and financial commitment from the government.

The expansion of outpatient capacity, which was done at the same time as the introduction of social support, enabled the additional numbers of MDR-TB patients to be seen closer to home and at a much lower cost facility than a hospital. This allowed the numbers of hospital beds to be reduced, which generated savings that could be used for outpatient care and patient support.

REFERENCES

- G. Kaliakbarova, S. Pak, N. Zhaksylykova, G. Raimova, B. Temerbekova, S. van den Hof, Psychosocial support improves treatment adherence among MDR-TB patients: experience from East Kazakhstan. *Open Infectious Diseases Journal*, 2013, 7 (Suppl 1:M7), 60-64
- WHO/EURO, 2013. Best practices in prevention, control and care for drug-resistant tuberculosis. A resource for the continued implementation of the Consolidated Action Plan to Prevent and Combat Multidrug- and Extensively drug-Resistant Tuberculosis in the WHO European Region, 2011–2015. (the experiences from East Kazakhstan are included in this compendium of best practices)

Governmental social support in Riga, Latvia

BACKGROUND

Latvia is one of the few high TB and MDR-TB burden countries that have been able to show that the incidence of both TB and MDR-TB are declining. This decline is attributed to a good TB control program in the country. The current estimates of MDR-TB are 11% (9-14%) among new patients and 32% (23-44%) among retreatment patients. At 16% the proportion of extensively drug resistant TB (XDR-TB) cases among those with MDR-TB is high. The majority of TB patients in the capital Riga have a low social status, exemplified by high rates of unemployment and alcohol abuse.

TREATMENT MODEL

In Latvia, TB and MDR-TB patients are hospitalized until they become non-infectious. Smear-negative TB patients do not require hospitalization, smear-negative MDR-TB patients are hospitalized during treatment initiation to get them settled into treatment, educate them, and address issues that could affect treatment in the outpatient setting. If the patient refuses hospitalization, home treatment can be organized if sufficient infection control measures can be implemented. During outpatient treatment, DOT is provided at a place suitable for the patient, e.g. at the family doctor.

OBJECTIVES OF PSYCHO-SOCIAL SUPPORT

The objectives of providing social support are to address the social challenges the patients face and improve adherence and treatment outcomes.

PSYCHO-EMOTIONAL AND SOCIO-ECONOMIC SUPPORT

After diagnosis, all patients in Riga are counseled on TB and its treatment, and the possibilities of getting social support. Contact details of HCWs including social workers involved in treatment and provision of social support are given to the patient, so they can contact them if they have further questions before the start of treatment. HCWs aim to involve family members in care, as experience has shown that those with support from their families have better treatment outcomes. Support is dependent on the patient's socio-economic status, and is tailored to the individual situation. All outpatients registered as inhabitants of Riga city are eligible for daily transport vouchers and food coupons.

A social worker employed by the TB hospital in Riga gives information about other social support available from the local government that might be useful to the patient. Examples of the socio-economic support provided are: temporary housing for the homeless, availability of free meals, provision of firewood for heating during the winter, free medical support for drugs to treat side effects, seeking collaboration with HIV NGOs to provide HIV-related treatment, seeking collaboration with alcohol and drug addiction specialists.

For patients not officially registered as an inhabitant, the social worker will help with 1. Obtaining the documentation (birth certificates, ID numbers, passports) required to access to social support from the local government, 2. Submitting them to social service department, and 3. Registering at a family doctor's practice. For unemployed inhabitants, a minimum social benefit allowance is available from the government. For those in employment, a sick leave allowance (usually 75% of salary) is available for a period of six months (although this can sometimes be extended). Patients with prolonged illness, including those for whom sick leave allowance is no longer available are eligible for a disability allowance.

RESULTS

Social support has been provided by national and local governments since 1997. Therefore, it is difficult to show the effect of social support on treatment adherence and treatment outcomes. However, as noted in the background section, Latvia is one of the few high MDR-TB burden countries that has been able to achieve a declining trend in both TB and MDR-TB incidence. From experience, program staff note that transportation vouchers really do improve adherence and thus

are enablers, while food coupons are considered incentives (nice to get, but not crucial for adherence).

FINANCING AND SUSTAINABILITY

The budget for the NTP is fully financed through the government, including social support provided to the TB patients. The required budget is estimated yearly and is based on the number of TB patients.

LESSONS LEARNED AND BEST PRACTICES

“To know your patient and to address their individual social, psychological and legal issues, helps to improve both individual and program results.”

The most important best practice is believed to be the multi-disciplinary but tailored approach to each patient, with political commitment shown by a legal framework including funding by the government.

The conditions and facilitating factors identified were:

- Professional training of all of those involved in the care of the TB patient
- Team work with the accountability of each team member for each case
- Case management based on a needs assessment
- An adequate number of staff for the existing workload
- Upfront calculation of the required funds
- A legal framework in place

Social support for MDR-TB patients in Namibia

BACKGROUND

Namibia is a vast country with a very low population density (2.6 people/km²) and long distances to health care facilities. The burden of TB disease is high (589/100,000 population) although the number of notified TB cases has been steadily declining over the past few years. The relatively high prevalence of HIV infection contributes significantly to the high prevalence of TB in the country. **Error! Bookmark not defined.**

Most TB patients are poor, unemployed and live in informal settlements. In Tsumkwe in the Otjozondjupa Region, MDR-TB disproportionately affects members of the San bushmen tribes (case notification rate for MDR-TB is 228/100,000 vs the national rate of 18/100,000). Poverty is increasing and the disease is spreading within families and to close contacts (anecdotal, from sources that default treatment). There are high levels of primary MDR-TB transmission, signified by high failure rates to first line regimens against a background of a high incidence of confirmed MDR-TB.

Despite the offer of universal and free access to treatment for drug-resistant TB by the Namibian government, default rates remain high and most patients cite psycho-social and financial challenges to continuing treatment.

TREATMENT MODEL

In the initial phase of treatment, patients are mostly hospitalized in district hospitals and may continue with ambulatory treatment if sputum smear or culture is negative and arrangements have been made to ensure daily DOT.

Most patients who live far from health facilities are hospitalized for the whole time they are on injections. If patients are not on injectables, they can choose to access care through health facility based DOT (integrated in PHC), workplace DOT, guardian-based DOT (by a home-based supporter), or other community based DOT, supervised by a trained CHW.

Special interventions were formulated for the nomadic San Bushmen in Tsumkwe, where a fully ambulatory treatment project for MDR-TB was introduced, with tents and food provided for the patients and their families, so that they are settled near to the clinic during treatment.

OBJECTIVES OF SOCIAL SUPPORT

To provide patients and their families support during treatment for MDR-TB.

PSYCHO-EMOTIONAL AND SOCIO-ECONOMIC SUPPORT

Social support services are provided by all HCWs at MDR-TB treatment sites, but mainly by social workers, community workers, rehabilitation officers, doctors and nurses. NGOs provide community based TB care services which complement the work of the NTP. The MDR-TB treatment site teams are trained to ensure the information shared is uniform, and members of the team get to interact and practice implementation.

Community based TB organizations employ DOT providers from local communities, who are well-placed to follow-up patients. In addition, in some districts, interventions are linked to Clinic Health Committees, which oversee the support being given to patients. In Tsumkwe, interventions followed community consultations.

Psycho-emotional support for patients with MDR-TB is described in the Strategic Plan and the National TB guidelines. Both inpatients and outpatients are entitled to counseling and access to support groups with:

- Initial assessment of all MDR-TB patients by social workers, includes individual counseling on adherence, implications of treatment, support structures, income and care of dependents
- Family counseling included to establish social support structures

- Ongoing follow-up assessment and counseling
- Social workers and rehabilitation professionals being part of designated PMDT teams and participate in ward rounds
- Skills training (beadwork, weaving) being available in some areas.

All MDR-TB patients are eligible for psycho-emotional support as well as TB patients with psycho-social issues. Psycho-emotional support starts soon after diagnosis and continues throughout treatment.

All patients with MDR-TB are also eligible for socio-economic support, as are TB patients with special needs. Almost all MDR-TB patients are hospitalized and priority is given to supporting them and their families as hospitalization often deprives patients of their regular income and there are high rates of defaulting (with frequent absconding from the hospitals). Support is made available after diagnosis, usually in the early stages of treatment.

Socio-economic support is available in different forms:

- A generic social disability grant, recommended by the social worker, endorsed by the doctor, and approved by the chief medical officer (on behalf of the Permanent Secretary of Health). Payment is processed by a separate ministry (Ministry of Labour and Social Welfare). The social worker is then responsible for the conditions of administering the grant. This is available while the patient is an inpatient as well as an outpatient
- All MDR-TB outpatients are eligible for nutritional support in the form of a fortified blended food
- Provision of ready-to-use therapeutic food packages for patients identified with malnutrition by the MoH and Social Services' Nutritional Assessment Counseling and Support (NACS) program
- Social security fund (from contributions by former employees) to protect from loss of income caused by illness. Available to inpatients and outpatients
- Other nutritional and income-generating projects depending on local NGOs.

The costs of transport and accommodation outside hospitals are not covered, but there are plans to introduce a system to reimburse transport costs.

RESULTS

Social support was implemented in 2011 in Tsumkwe and in 2012 nationwide. In Otjozondjupa, where the Tsumkwe project for the San nomad bushmen was started, the loss-to-follow-up rate fell from 27% in 2009 to 12% in 2011 (when the best practices started). Preliminary nationwide data for 2013 indicate that loss-to-follow-up rates reduced from 12% in 2011 to 5% in 2013. All 307 MDR-TB patients in 2013 were eligible for support but figures were not available for numbers of patients who actually received it. No specific data on treatment adherence is available nationally.

FINANCING AND SUSTAINABILITY

The Government funds training, social disability grants, social security grants and all the direct costs of diagnosis and treatment.

Development partners (USAID TB CARE I) fund training and indirect funding through some community-based TB care (CBTBC) NGOs.

The Global Fund supports fortified blended food and indirect funding through most CBTBC NGOs. Donor funding depends on availability.

LESSONS LEARNED AND BEST PRACTICES

No formal evaluation of the interventions has been done, but the respondent believes that this intervention makes patients more likely to start treatment, improves treatment outcomes and reduces default rates. In addition, patients with MDR-TB find it easier to seek diagnosis and

treatment with the support available, that eventually reduces transmission of MDR-TB in the community.

The best practices described here are aimed at giving HCWs and support staff the confidence and tools to manage the mostly psycho-social challenges faced by MDR-TB patients. They also show the commitment of the government and the NTP to social support.

The best practices are as follows:

- Sensitizing all social workers on the importance of this support for TB patients. This involved specially designed trainings on basic TB facts and consultative workshops on patients' needs.
- Recruiting a social worker designated as a treatment support coordinator at the NTP level.
- Training multidisciplinary teams (social worker, doctor, nurse, TB coordinator, rehabilitation officer or occupational therapist, environmental health officer, and community based workers). This helped psycho-emotional support providers to deal with patients holistically, and to recognize their non-medical needs. This mix of professional and lay people in training may be resisted but is vital for an effective program.
- Ensure all MDR-TB patients have social assessments and counseling prior to starting treatment, to detect potential barriers to treatment before they become manifest.
- All available resources (e.g. disability pensions) should be explored, including those not specifically for TB patients (such as social support systems for the poor), and to then advocate for their use in the economic support of MDR-TB patients

The main challenges encountered were a lack of support for patient transport costs for DOT and/or medicine pick-up and the difficulty in designing a uniform model for transport given the sparsely distributed population.

REFERENCES

- NPC. Namibia 2011 Population And Housing Census Namibia 2011 Population and Housing Census Preliminary Results. Windhoek: National Planning Commission; 2012.
- MoHSS. Second Medium Term Strategic Plan for Tuberculosis and Leprosy (2010-2015). Windhoek: Ministry of Health & Social Services; 2010.
- MoHSS. National Guidelines for the Management of Tuberculosis. 3rd ed. Windhoek: Ministry of Health & Social Services; 2012.
- Namibia Statistics Agency. Namibia Household Income & Expenditure Survey (NHIES) 2009/10. Windhoek; 2010.
- Verduin R, Vaughan K. Community-Based Tuberculosis Care Assessment Namibia 2013-2014. Windhoek; 2014.

Fund for Special Needs in The Netherlands

BACKGROUND

The Netherlands is a low TB incidence country, the overall estimated TB incidence is 5.1 per 100,000 population. As in many low incidence countries, the majority of TB patients (75% in recent years) are foreign-born. The prevalence of MDR-TB is low, below 2% overall, approximately 15-20 patients per year.

TREATMENT MODEL

As with other infectious diseases in the Netherlands, TB is diagnosed and treated in the routine health care system. Public health services are responsible for screening risk groups and carrying out contact investigations. They also usually treat patients that are actively detected. In principle TB treatment is ambulatory, but MDR-TB patients are usually hospitalized during the first months of treatment in one of the two TB clinics.

OBJECTIVES OF SOCIAL SUPPORT

To help or motivate patients to adhere to treatment through provision of enablers and incentives, with the aim of improving the chances of treatment success.

PSYCHO-EMOTIONAL AND SOCIO-ECONOMIC SUPPORT

Health insurance is mandatory for everyone in the Netherlands, and it covers many health care costs, except for a yearly amount of deductible excess (i.e. the first costs under this excess amount you have to pay yourself). Beyond the excess, TB treatment including hospitalization costs are covered by health insurance.

The socio-economic support in the form of enablers and incentives is part of a broader approach which also includes psycho-emotional support. All TB patients are eligible for this additional type of support. Receipt of this support is initiated by TB nurses or social workers associated with the TB hospitals, for those patients they feel would benefit from it.

They apply to KNCV for specific types of enablers and incentives, tailored to the patients' needs. KNCV is one of the recipients of the TB program budget disbursed by the MoH, but this fund does not come from this budget.

Some specific examples of enablers and incentives provided are:

- Pocket money to buy extra food
- Travel costs to visit physicians or a DOT center
- Travel costs for family/friends, so they can visit the patient in TB clinics
- A bike to make it possible to visit the DOT center (and at the same time to provide exercise to improve physical health)
- A watch so that they are on time for DOT appointments
- Incentives to motivate people to adhere to treatment (i.e. telephone card so patients can keep in contact with family abroad for social support, small presents for children such as coloring books and pencils)

RESULTS

No formal evaluation on the effects on treatment adherence has taken place.

The budget holder always tries to find other potential sources (e.g. transport costs from health insurance, municipal funding sources for vulnerable groups, etc.)

About a third of the funds are spent on requests related to travel costs, and about a quarter on requests related to food support.

Some patients make several requests during treatment, so we are unable to calculate the proportion of patients for whom one or more requests were received.

Foreign born patients, and especially asylum seekers, are overrepresented in the number of requests, reflecting their socio-economic status.

FINANCING AND SUSTAINABILITY

The annual budget for this support comes from the 'Funds for Special Needs', which is financed from equity interest yields and revenues from the national charity lottery. The budget has remained constant at around €20,000 for the last decade and the average amount disbursed per request has is around €150.

LESSONS LEARNED AND BEST PRACTICES

Considering the number of applications, the practice clearly responds to a need. The respondent frequently hears from TB nurses and social workers that patients feel supported by the Fund's contributions. When patients do not have a financial or social network, the support of the Fund is especially felt to be of great importance for treatment adherence.

Patient-Centered Approach Package

PILOT IMPLEMENTATION OF A PATIENT-CENTERED APPROACH PACKAGE IN FIVE COUNTRIES (CAMBODIA, INDONESIA, MOZAMBIQUE, NIGERIA AND ZAMBIA)

BACKGROUND

Patient-centered care demands that the patient is respected as an individual, is engaged in his/her care, they are informed about illness and their personal situation is taken into consideration to design necessary interventions.

Patient-centered care is the focus of the first pillar of the WHO's post 2015 End TB Strategy, but putting it into practice can be challenging. Health facilities are very busy and sufficient time is often lacking to provide information on TB disease, its effect on one's life and the importance of adherence. HCWs often do not have the capacity to provide quality counseling and interact with patients in a compassionate manner. In turn, patients do not feel empowered enough to ask questions and/or demand better services.

PATIENT-CENTERED APPROACH PACKAGE

TB CARE I recognized the importance of applying a patient-centered approach and responded with a package of tools developed by its partners for national programs and local partners to facilitate implementation of a PCA to TB control. TB CARE I PCA package consists of five tools and a booklet that explains the concepts behind the approach:

1. The Patients' Charter for Tuberculosis Care and Control (the Charter)
2. TB/HIV Literacy toolkit (the Toolkit)
3. QUOTE TB Light
4. Tool to Estimate Patients' Costs and
5. Practical Guide to Improve Quality TB Patient Care¹

The PCA package is designed to facilitate increased patient-centered care at the country level. The first two tools inform patients on their rights and responsibilities (the Charter) and about TB/HIV (the Literacy Toolkit) and its effect on their lives. The subsequent two are developed to understand needs for better services and costs related to TB services.

The PCA package was piloted in 2012/2013. Countries which took part in this pilot over a six month period were Cambodia, Indonesia, Mozambique, Nigeria and Zambia. Each country selected 2-3 tools for implementation. All five countries selected the Patients' Charter and QUOTE TB Light; two countries also selected the TB/HIV Literacy toolkit and two countries selected The Tool to Estimate Patients' Costs. The pilot was implemented in two districts of each country—at health facility and community levels.

The main activities carried out to pilot The Patients' Charter and the TB/HIV Literacy Toolkit of the PCA package were related to the use of these tools during patients-HCWs interactions at TB treatment initiation, during workshops held for patients' groups and health care providers as well during community health education sessions.

The Charter was shared with patients at the initiation of TB treatment and during follow-up visits through workshops/group sessions held with patients and with HCWs. The Charter was observed to be tool of empowerment as it enabled patients to open up, ask questions and in some cases demand more attention from the HCW to attend their needs.

¹ This tool is a guide consisting of self-assessment tools to help HCWs improve their skills in applying a PCA; it is based on the Evidence-based Participatory Quality Improvement (EPQI) methodology. It was not selected by any of the five countries as it was found to be too complex.

As with the Charter, the TB/HIV Literacy Toolkit was used at the initiation of TB treatment, in group sessions with patients and in the community meetings on health education. The Toolkit was designed to facilitate dialogue among patients and HCWs to help patients better understand the information provided. Both QUOTE TB Light and the Tool to Estimate Patients' Costs are measurement tools and were implemented as operations research studies. A sample of patients was selected according to the guidelines within the tools.

QUOTE TB Light was implemented in three steps with TB patient participation; focus groups discussions rank the importance of nine quality dimensions; interviews to score the performance of the health facility and a final calculation of the importance and performance scores for the quality impact score, which directly indicates which elements of TB services are in need of improvement.

Patients' interviews were held to estimate costs related to TB illness, using the Tool to Estimate Patients' Costs.²

The Charter and the Toolkit were implemented by nurses, community volunteers, (ex) patients and HCWs who underwent training on basic health literacy and counseling/facilitation skills. QUOTE TB Light and the Tool to Estimate Patients' Costs were implemented by researchers and Civil Society Organizations (CSOs) with the capacity to carry out operations research.

RESULTS

To measure the effect of implementing the PCA package there was pre-/post-study to look at changes towards increased patient-centered care. Indicators for this study were: knowledge of patients' rights; perception of quality of services; knowledge of TB; perception of barriers to accessing services and experience of stigma.

Results showed that there was increased awareness among TB patients about patients' rights and knowledge on TB. Perceptions of quality of services, barriers to access services and stigma did not change. However, HCWs' awareness of the need TB patients have for quality services and the barriers to service access increased.

FINANCING AND SUSTAINABILITY

The PCA package was developed and piloted with financial support of USAID under the TB CARE I project.

As each of the five countries have plans to scale up, and the approach should be eventually integrated into national policy and TB guidelines, extra budgets are necessary to train people, develop plans, engage stakeholders and monitor outcomes.

BEST PRACTICES AND LESSONS LEARNED

- Patient-centered care implies continuous health education and community involvement. There is a real need to empower patients and their communities with knowledge about TB
- The studies showed that education activities within health facilities and in the community should be strengthened; HCWs should be made aware of TB patients' needs regarding information/counseling on TB (infection, transmission, diagnosis and treatment). Involving patients and CSOs in the planning, implementation and monitoring of TB education activities is crucial in terms of empowerment and creating demand for better services
- Tools should be selected based on the experiences from this pilot, but additional tools can also be considered as all have been found to be effective in supporting increased patient-centered care. It was suggested to add more in depth information on types of stigma and its root causes in different cultures. The Tool to Estimate Patients' Costs was valuable, but the country

² Tool developed under the TB CAP project. Note that a revised version was developed under the TB CARE I project

implementers in Indonesia and Nigeria requested that the design be revisited and a simplified version developed

- Specific implementation guidelines should be developed for each country that take their specific contexts and needs into consideration. The guidelines should include simple, user friendly steps to be followed during implementation. A strategy with practical standard operating procedures including objectives, benchmarks, and the roles and responsibilities for the implementation and monitoring of a PCA should be developed
- Revise tools and include a section on the next steps to be taken once preliminary results are known
- Use study results to develop the necessary interventions and scale up to the national level.

Social support for MDR-TB patients in Peru

BACKGROUND

Peru has an estimated annual TB incidence of 95 per 100,000 population. The estimated proportion of patients with MDR-TB is 3.9% (3.6-4.2%) among new patients and 35% (33-37%) among previously treated patients, giving an estimated annual number of 2200 (2000-4000) MDR-TB patients.

DOTS has been a successful strategy in curing TB patients in Peru but many MDR-TB patients do not adhere to treatment for psycho-socio-economic reasons. Reasons include poverty, the cost of accessing treatment and food, poor housing conditions, discrimination and other problems such as alcohol, drugs and delinquency.

TREATMENT MODEL

All MDR-TB patients receive outpatient treatment in MoH facilities. Before they start treatment, they must have received guidance and counseling, and signed an informed consent form. The administration of medication is supervised. Hospitalization only takes place when there are major complications, such as a severe form of hemoptysis. In cases where patients have significant difficulty in attending, health facility staff go to patients' homes or request assistance from CHWs. Patient medications, exams and procedures, are provided free of charge by the Government, both in the outpatient stage and during hospitalization.

OBJECTIVES OF SOCIAL SUPPORT

Improving the adherence rate among people reached with the donor-funded program and reducing the economic burden to patients and their families.

PSYCHO-EMOTIONAL AND SOCIO-ECONOMIC SUPPORT

All XDR-TB patients and MDR-TB patients who are deemed likely to abandon treatment, are a priority for support.

Psycho-emotional support. The program's main activity are psycho-emotional support groups, where patients can verbalize their problems and receive support from peers, family members, cured patients and the therapeutic team. These groups help to reduce patient fears, anxiety, guilt and other negative emotions associated with the abandonment of treatment. They also help patients to improve their ability to cope with adverse situations and better manage the effects of treatment.

All MDR-TB patients are eligible to join these groups, after at least two consecutive negative cultures. Participation is voluntary and patients can participate until they finish treatment or longer if they wish to. Psychiatric patients are referred to specialists.

The support team is multidisciplinary but most of the staff are nurses and social workers. CHWs play a vital role, providing DOTS, ensuring the adherence and commitment given with socio-economic support, and by participating in the organization of the psycho-emotional groups.

Socio-economic support. The socio-economic support is given according to the needs of the patient and covers inpatients as well as outpatients. All MDR-TB patients are eligible for support if it is determined that they could potentially abandon treatment because of their socio-economic conditions. The decision is made by the project's Social Protection Program team and a social worker from the health center. They make a home visit and use a standard socio-economic evaluation. Once it is shown that a patient needs the program, a commitment of support is made for a three-month period, with the possibility of renewal if possible problems of patient adherence are evident.

Socio-economic support is initially sought from the government social program and if that is not available, patients are given cash transfers which are conditional on the correct adherence to treatment. To receive this benefit, patients have to meet the CHW for their daily treatment; if the patient fails to turn up, the benefit is withdrawn. This is supposed to cover their urgent domestic

needs. Support can also be specific, such as nutritional supplements or assistance to set up a separate room for the patient and to buy a bed and/or mattress.

The conditional transfer program is on average \$100/month, which is roughly equivalent to one month's loss of income. However, other specific support, such as creating a space for a patient room, can cost around \$3,000. Currently this is only funded by the Global Fund and Partners in Health. All expenditure on drugs and procedures are provided free by the government.

RESULTS

The number of patients who can be supported depends on the resources available to the program. In 2013, 174 patients were reported and started treatment. All of the XDR-TB patients and 50% of the MDR-TB patients received both psycho-social and socio-economic support. So far, the project has reported 21 patients with adherence problems.

In our last evaluation, the numbers of XDR-TB defaulters was zero and the number of MDR-TB defaulters had decreased from 17% to 10%. This is a positive result, especially when the fact that the patient group involved was at a higher than average risk of defaulting is taken into account.

The improvement in adherence under the donor-funded program has not yet been reflected in the rest of the country, where loss-to-follow-up remains high. As a result of this program in Lima, the national government has increased the financial commitment for mental health and social protection in the country.

FINANCING AND SUSTAINABILITY

The funding for socio-economic and psycho-social support is supposed to come from government social programs although their support is very limited compared with the need. Therefore, funding is mostly provided by donors but has been reduced over time, meaning current funding and sustainability are issues.

LESSONS LEARNED AND BEST PRACTICES

A number of lessons and best practices have been learned:

- The commitments established with the patients in exchange for socio-economic support were strong because they were made clear at the beginning and commitment documents were signed.
- It is best to focus support on patients who are most likely to abandon treatment and it is important to have good tools to select those patients, especially where resources are limited.
- The needs for socio-economic and psycho-emotional support are different between patients, so it is important to know each patient well – including their history and family situation.
- It is better to provide cash instead of goods or services in kind (e.g. food) because the patients know best what their needs are. It is recognized that giving cash can be a risk and it is important to assess each case for the possible misuse of funds. The rules about removal of support for non-compliance are clear and so the patients generally keep to that agreement.
- The staff involved in providing support should have community experience and be professionally trained. They must be able to empathize with patients and their families.
- It is important to involve CHWs as part of the support provider teams.

One of the challenges is that there is no regulatory framework to guide these socio-economic and psycho-emotional programs. Children with MDR-TB bring extra challenges due to the difficulties of diagnosis and a lack of pediatric treatment formulations.

Where social support is provided by NGOs it is important to work closely with the MoH and other stakeholders (such as local governments), to ensure the sustainability of the intervention. This has

helped to show the need for and the success of the program and is resulting in increased interest and financial commitment from the government.

REFERENCES

- Mitnick CD, Franke MF, Rich ML, Alcantara Viru FA, Appleton SC, Atwood SS, et al. Aggressive regimens for multidrug-resistant tuberculosis decrease all-cause mortality. *PLoS One*. 2013;8(3):e58664.
- Mitnick CD, Shin SS, Seung KJ, Rich ML, Atwood SS, Furin JJ, et al. Comprehensive treatment of extensively drug-resistant tuberculosis. *N Engl J Med*. 2008 Aug 7; 359(6):563-74.
- Acha J, Sweetland A, Guerra D, Chalco K, Castillo H, Palacios E. Psychosocial support groups for patients with multidrug-resistant tuberculosis: five years of experience. *Glob Public Health*. 2007;2(4):404-17.
- Chalco K, Wu DY, Mestanza L, Muñoz M, Llaro K, Guerra D, et al. Nurses as providers of emotional support to patients with MDR-TB. *Int Nurs Rev*. 2006 Dec;53(4):253-60.
- Palacios E, Guerra D, Llaro K, Chalco K, Sapag R, Furin J. The role of the nurse in the community-based treatment of multidrug-resistant tuberculosis (MDR-TB). *Int J Tuberc Lung Dis*. 2003 Apr;7(4):343-6.
- Palazuelos D, Ellis K, Im DD, Peckarsky M, Schwarz D, Farmer DB, Dhillon R, Johnson A, Orihuela C, Hackett J, Baile J, Berman L, Ballard M, Panjabi R, Ternier R, Slavin S, Lee S, Selinsky S, Mitnick CD. 5-SPICE: the application of an original framework for community health worker program design, quality improvement and research agenda setting. *Glob Health Action*. 2013 Apr 3;6:19658. doi: 10.3402/gha.v6i0.19658.

Patient-Centered Accompaniment in Voronezh, Russia

BACKGROUND

The Russian Federation had an estimated TB incidence of 91 per 100,000 in 2012. The estimated proportion of MDR-TB cases is 23% (21-25%) among new patients and 49% (44-53%) among previously treated cases. Of the estimated 45,000 MDR-TB cases among TB patients notified in 2012, only 13,612 were actually diagnosed with MDR-TB. Side effects from TB medications, low motivation for TB treatment as well as poor access to TB services, are major reasons for the interruption of treatment.

Voronezh city has a population of 1 million, in 2011 the notification rate of all forms of TB was 35.1 per 100,000. In 2011, more than 400 urban TB patients were being treated, including 220 as outpatients.

TREATMENT MODEL

TB treatment is delivered in both inpatient and outpatient settings. Currently, the majority of smear-positive patients remain in hospital until smear-negative and socially disadvantaged individuals can remain for the duration of treatment. Patients usually receive DOT at the City TB Dispensary or in the rural ambulatory clinics for those living in the suburbs.

OBJECTIVES OF SOCIAL SUPPORT

The objective is to ensure treatment adherence throughout treatment through regular supervision and support. In Voronezh the patient-centered accompaniment approach (PCAA) mainly focuses on MDR-TB patients with adherence problems during outpatient treatment. However, some other patients deemed to be at risk of defaulting were also enrolled.

PSYCHO-EMOTIONAL AND SOCIO-ECONOMIC SUPPORT

Within the Voronezh TB Service a PCAA system was established in February 2011 providing a complex of patient-centered services:

- DOT at the patient's home or at any other location requested by or suitable for the patient. If a patient is absent from a scheduled meeting the project staff searches for the patient based on the knowledge of his/her habits and interests.
- Daily food packages to motivate patients to continue treatment.
- Establishing trusted and open relationships with patients and their families, friends and neighbors.
- The PCAA team provides additional medical, psychological and social support by connecting patients with local resources available to all patients.

Patients facing treatment difficulties, including non-adherence, are discussed at weekly clinical committee meetings. Patients eligible for the PCAA model are patients with low adherence, who stopped treatment 1-1.5 months ago, and smear-positive patients who refuse treatment.

Psycho-emotional support is available for all TB patients at the start of treatment, with close follow-up for problematic patients. Patients have access to a substance abuse specialist, a psychologist and a social worker. Before the PCAA program was in place, this type of support had only been provided for patients with official psychiatric diagnosis (e.g. alcoholism or narcotic dependence).

Socio-economic support for outpatients in the PCAA program consists of supplying daily food packages when patients receive their full dose of medications (provided at a suitable place for the patient). Before the PCAA program, food packages were not available for drug-susceptible TB patients.

FINANCING AND SUSTAINABILITY

There are two PCAA teams covering different city areas, each team includes a driver, nurses and a doctor and takes care of an average of 15-20 patients at a time.

At the start in February 2011, one PCAA team was 100% financed by a USAID Grant with coordination by Partners in Health (PIH, USA-Russia). From 2012, the project was co-funded by ELI Lilly MDR-TB Partnership, and a second PCAA team was funded by the local funding through the MoH. In 2013, \$40,000 donated by PIH/Eli Lilly covered the cost of food packages (\$40 per month per patient), mobile phones and contracts, side effect medications, and gasoline for the PCAA team vehicle. Voronezh provides funding for the cost of a second team plus salaries for both teams.

The PCAA project had been previously implemented in Tomsk (the primary PCAA site for the "Sputnik" project) and Petrozavodsk, Republic of Karelia and the Russian Federation.

Conditions for scale-up identified by PIH are:

- Political commitment, with long-term planning, from the TB administration and regional office of the MoH
- Adequate human resources
- Expanded and sustainable financing
- An efficient monitoring system for the program supervision and evaluation, including measurement of impact.

RESULTS

From February 2011 to December 2013, the total number of patients enrolled into the project reached 142. The proportion of all patients treated under the PCAA program increased gradually. In 2013, 40 patients received treatment via the PCAA Program in Voronezh, accounting for almost 30% of all patients undergoing outpatient treatment (141 people). Of these, there were 37 patients with MDR-TB, accounting for 55% of all MDR-TB outpatients treated by the city TB service (67 patients).

Patients treated via the PCAA program had a high risk profile (e.g. alcohol dependence, drug addiction, loss-to-follow-up during previous treatment, etc.). However, no data were available to compare the risk profile of those in the program with that in the full treatment cohort.

Patients' adherence before the referral to PCAA Program was recorded at 50%, 57% and 60% in 2010, 2011 and 2012 respectively. Adherence under the PCAA program was 75%, 83% and 81% respectively, for the same time period.

The proportion of MDR-TB patients with sputum conversion at the end of the year increased from 30-40% for the 2009-2011 treatment cohorts to 60% for the 2012 treatment cohort. Final treatment outcomes were available for 81 of 142 patients enrolled in the PCAA in 2011-2012. Of those, successful outcomes were reported for 73 (90%) patients, 5 patients (6%) died of causes other than TB, and 3 persons (4%) were lost-to-follow-up.

LESSONS LEARNED AND BEST PRACTICES

Although the results are encouraging, significant challenges to the scale up and implementation of a patient-centered model of care for MDR-TB remain. The PCAA model requires:

- A policy and regulatory framework that is designed to support the delivery of patient-centered care
- Commitment, innovation and leadership from clinicians and managers across the system
- Partnership in many forms: between patients and clinicians, and between different professions, health sectors and social care.

This approach of intense accompaniment is considered to offer a viable and affordable alternative to the compulsory treatment of non-adherent patients without the human rights implications and the risk of nosocomial transmission.

The respondents identified the following recommendations for the delivery of person-centered care:

- Sustain efforts to increase staff trainings to improve technical skills and encourage behavior change
- Strengthen the leadership of the people responsible for TB treatment, in order to achieve excellence in the delivery of services
- Strengthen the principle of co-responsibility between the health personnel and TB patients
- Provide additional services (social, psychological and addiction) in response to patients' psycho-social needs.

Social support for MDR-TB patients in Rwanda

BACKGROUND

In 2012 Rwanda had an estimated TB incidence of 86 per 100,000 and 26% of patients were HIV-co-infected. The estimated proportion of MDR-TB cases is 3.9% (2-5-5.8%) among new patients and 19% (15-23%) among previously treated cases. This adds up to an estimated 243 MDR-TB cases among TB patients notified in 2012, while in that year only 58 were diagnosed with MDR-TB. Patients with MDR-TB often experience delays in diagnosis, meaning the disease has already severely affected their clinical conditions, and when they have used up their economic resources. The long treatment time also has a negative socio-economic impact for the patient and their family.

TREATMENT MODEL

All MDR-TB patients initiate treatment in specialized MDR-TB centers. After sputum conversion (three consecutive negative sputum microscopy and at least one negative culture) patients are discharged to continue the treatment in ambulatory phase at a health facility close to their home, where DOT is ensured. Currently just over 100 MDR-TB patients are on treatment in the country.

OBJECTIVES OF SOCIAL SUPPORT

The objectives of providing support to MDR-TB patients are

1. To allow the patient to understand that the disease is curable, and that he/she will be able to resume normal life after the completion of treatment
2. To allow the patient to adhere to treatment
3. To allow the patient to reintegrate back into their normal socio-economic life after treatment.

PSYCHO-EMOTIONAL AND SOCIO-ECONOMIC SUPPORT

Psycho-emotional support is provided throughout treatment:

- After MDR-TB diagnosis, individual counseling includes health education on the disease, possibility of treatment, duration of treatment and the mode of treatment. The patient is advised to begin treatment as soon as possible
- Upon entering the MDR-TB center at district level another individual counseling session is organized
- During hospitalization at the MDR-TB center, group counseling led by an MDR-TB psychologist or one of the nurses is carried out weekly
- During ambulatory care, the health center providing DOT is mainly responsible for counseling.

Socio-economic support is also provided throughout treatment:

- Hospitalization is free and clinical exams, drugs, food and hygiene materials are provided free of charge during hospitalization
- During ambulatory treatment, patients are provided with drugs, clinical exams, free medical insurance (that covers all medical costs, including 90% of costs for family members), transportation fees, nutritional support (food packages) and if needed, housing is also provided.

All support has been provided since the start of MDR-TB treatment in 2005. Since 2012, patients have been provided with phased nutritional support for the first six months after the completion of treatment to help patients reintegrate into normal life.

FINANCING AND SUSTAINABILITY

Initially all patient support was provided by the government, Global Fund support came later and took over one part of the support. The government ensures basic infrastructures are in place (MDR-TB centers/buildings, health facility staff salaries, etc.) while the Global Fund covers financial support (drugs, nutrition and transportation fees). The government is committed to continuing

support for MDR-TB patients when other donors have left. Financial support is disbursed by the national TB Division to the health facility on a quarterly basis. Patients discuss how best to use the financial support with the health facility.

RESULTS

Patient support has been provided since MDR-TB treatment began in Rwanda, so no data exist to show its effect on treatment adherence and treatment outcomes. However, adherence and treatment success is reported to be high: treatment success was 88.7% for MDR-TB treatment cohorts 2005-2011. Because of the level of experience Rwanda has attained, it hosts the East African Regional Center of Excellence in the Programmatic Management of MDR-TB.

LESSONS LEARNED AND BEST PRACTICES

All MDR-TB patients diagnosed and started on treatment have been provided with free treatment, transport and nutritional support and no main challenges to implementation have been identified. The success of MDR-TB management in Rwanda can be associated with the strong political commitment to overcome the problem, early diagnosis of the disease and psycho-socio-economic support to patients.

Social Support to Strengthen Outpatient Care in Tajikistan

BACKGROUND

Tajikistan has one of the most serious TB problems in the WHO European Region with 108 new cases per 100,000 population and an estimated mortality of 7.6/100,000 in 2012 (excluding TB/HIV cases). **Error! Bookmark not defined.** It is also one of the 27 high burden MDR-TB countries in the world and 10% of MDR-TB cases are XDR-TB. The number of MDR-TB and XDR-TB cases continues to rise.

The majority of TB and MDR-TB patients are poor. Loss-to-follow-up of TB treatment is common, with a principal reason being the necessity to migrate in order to find employment.

TREATMENT MODEL

The key elements of the MDR-TB treatment model are as follows:

- After 2-3 months in hospital, patients usually continue treatment as outpatients. Some patients refuse hospitalization and are treated as outpatients from the start
- Most patients receive treatment at PHC facilities, but a few at use TB centers. The decision is based on where the live
- Treatment is daily – both at facilities and at home.

OBJECTIVES OF SOCIAL SUPPORT

The objectives of providing social support were to strengthen ambulatory care,³ reduce default rates and improve treatment adherence.

PSYCHO-EMOTIONAL AND SOCIO-ECONOMIC SUPPORT

Before 2014 only needy patients received **psycho-emotional support during hospitalization**, the key elements of which are as follows:

- Patient support team established under the national MDT-TB Technical Working Group with a sub-group for outpatient care. Members were trained on inter-personal communications and went on educational visits out of-country
- During the ambulatory care period psycho-emotional support (individual and group conversation and consultation) is implemented by the medical providers of PHC facilities, and community and religious leaders
- Risk assessments for treatment interruption are made at the beginning of treatment and support is based on the results. Support continues throughout the whole treatment period
- Community groups including local authority staff and medical workers decide which patients need support and what kind of support
- TB and MDR-TB patients who are eligible for support are patients who are poor, have severe side-effects, have secondary/chronic diseases and those predisposed to treatment interruption or cessation
- Issues on providing social support to TB and MDR-TB patients are discussed at monthly local government meetings and progress reports are prepared.

In 2014 the following elements of **socio-economic support** were added:

- Local government exempts patients from electricity bills, land-taxes, garbage removal charges and water supply payments. In addition families are provided with firewood, extra land for growing vegetables and assistance in the construction of a separate room for the patient. A small amount of monthly financial support is also provided. At the request of local government, farmers provide TB and MDR-TB patients with monthly food supplies

³ Note that social support will result in reduced costs if it means that patients can be successfully treated as outpatients rather than having to keep patients in hospital.

- Advocacy has led to the inclusion of TB treatment as a criterion for sick leave allowance
- In addition food and hygiene parcels (funded by USAID) are provided to all MDR-TB patients as well as those drug-susceptible TB patients in need.

RESULTS

In 2013 all 50 registered MDR-TB cases in the patient support pilot sites (five districts) were eligible for psycho-emotional support and 47 (94%) of them received support. In 2014 January-August all 47 registered MDR-TB cases were eligible and 46 (99%) of them received it. For drug-susceptible TB patients, support was more limited due to the restricted financing abilities of local government, with 102 out of 230 (44%) eligible patients receiving support in 2013 and 89 out of 120 eligible patients (74%) in 2014.

As yet, no evaluation on the effects of this support has been conducted and there is no information on the impact on rates of diagnosis-seeking, treatment seeking, treatment adherence and treatment completion.

FINANCING AND SUSTAINABILITY

The annual municipal government budget includes funds for social support which can cover support for TB and MDR-TB patients. These are being used to support some patients (the number depends on the availability of funds) which indicates a strong commitment for support in principle and bodes well for sustainability, providing sufficient funding can be allocated in the future.

LESSONS LEARNED AND BEST PRACTICES

The most important best practice is believed to be the involvement and commitment of local government and communities in the provision of psycho-socio-economic support. This approach had not been tried before and gave positive results as well as contributing to the sustainability of patient support system.

The best practices identified by the respondent are:

- The development and implementation of protocols on strengthening ambulatory treatment and psycho-social support for TB patients
- The elaboration and implementation of local government orders on the improvement of ambulatory treatment and social support for TB patients
- The use of standard criteria for the selection and implementation of psycho-socio-economic support
- The use of community groups to help select patients who need support and to manage the social support program
- The coordination of social support from local government (municipalities and districts), and close collaboration between medical workers from the primary health care facilities (physicians, nurses, responsible specialists for DOTs and sputum collection), TB specialists, community activists and religious leaders.

The main challenge has been the shortage of qualified psycho-socio-economic support providers and the fact that the treatment of only about 60-70% of TB patients is directly observed by medical workers.

Key Findings

The main findings from the ten programs are summarized in Table 1 (see page 39). Social support was mainly implemented for patients on MDR-TB treatment. Most of the initiatives were set up to address the treatment adherence barriers faced by patients, through the provision of several components of psycho-socio-economic support. Only two programs, Indonesia (case study 1) and the multi-country project on the PCA (case study 6), were focused mainly on TB education/information support, and aimed to improve adherence to treatment through acquisition of knowledge and skills to cope with the challenges of treatment.

In all the programs interventions were managed by multidisciplinary teams comprised mostly of social workers, psychologists and nurses. Virtually all the programs reported having educational and psychological components. The programs were mainly designed to address the most immediate obstacles to patients' adherence; interventions to address stigma and discrimination were not explicitly reported.

The different resources and contexts in the countries explain the differences in the services delivered in each program. Due to limited resources, most programs had to prioritize the patients most in need in of support, or likely to be lost-to-follow-up, and had systems for identifying those patients. Most programs tried to tailor some elements of support to individual patients' needs, while some forms of support (such as food packages and transport vouchers) were made available to all patients. Some programs developed detailed procedures for the identification of patients' needs and the design of patient-centered support packages, such as in Kazakhstan (case study 2)

Reducing patient costs during treatment was not an explicit goal of any of the programs, but such a reduction was an obvious by-product of the interventions as most of them included the provision of assistance in cash or in kind, or by reducing other household costs such as tax exemptions in Tajikistan - (case study 10). Cash transfer schemes are being implemented by some programs, either through parallel systems in Peru (case study 7) or as part of a well-established national social protection scheme such as in Kazakhstan (case study 2). In both examples the transfers are reported to be conditional on adherence to treatment. Cash transfers and microfinance programs are innovations that have proven to be effective in removing people from absolute poverty in Latin American and Caribbean countries.¹⁵ Their contribution to preventing catastrophic costs or alleviating poverty in TB patients deserves further investigation.¹⁶

Effectiveness: Most programs provided enablers and incentives, counseling, social services, and financial or in kind assistance. The case studies largely lacked quantitative evidence on effectiveness of the interventions on treatment success, but several case studies were able to show improved adherence. For example, in Vonorezh (case study 8) and Kazakhstan (case study 2), patients who received support showed improved treatment adherence, and results from Indonesia (case study 1) and Namibia (case study 4) indicate less loss-to-follow-up. More qualitative descriptive results strongly suggest that the social support interventions do contribute to improved treatment outcomes, such as in Latvia (case study 3) and Peru (case study 7).

Sustainability: Conditions for sustainability, and thus national scale-up, were reported as being political commitment, dedicated of financial and human resources, and the presence of a legal framework to enable the provision of psycho-socio-economic support for patients in need. In Kazakhstan (case study 2), Latvia (case study 3), Namibia (case study 4) and Rwanda (case study 9) patients have access to established generic (not specifically for TB patients) social protection schemes put in place by governments. In Kazakhstan (case study 2), TB patients were eligible for specific NTP-initiated support fully funded through the local government; while a mix of government and donor support is used in Namibia (case study 4) and Tajikistan (case study 10). External support through bilateral or multilateral donors remains the main source of funding for the other interventions described. In the Netherlands (case study 5) a charitable "special needs"

fund is used to complement (and leverage) other resources from local governments and health insurance on a case by case basis.

Experience from Kazakhstan (case study 2) shows that building an evidence-based case during the pilot phase can generate political commitment for scale-up.

Possibility for scale-up: In addition to the requisites for sustainability, scalability requires general acceptability of the intervention, adaptability to local circumstances, the intervention not being too resource intensive, and integration into national legal frameworks and local structures.

In Indonesia the involvement of former patients in communication training (case study 1) is included in the national training package; however at the time of this survey the limited capacity of trainers was still an obstacle for scale-up. Kazakhstan (case study 2) started scale-up of the piloted psycho-socio-economic support interventions and included this in their new, largely domestically funded, national strategic plan. A specifically developed national legal framework underpins social support for TB/MDR-TB patients in some countries, e.g. Latvia (case study 3) and Namibia (case study 4). In Tajikistan (case study 10), TB treatment was included as an eligibility criterion for sickness leave allowance.

Some pilot projects have as yet been unable to secure sustainable local resources for scale-up, notably the multi-country social support packages project (case study 6), Peru (case study 7) and Voronezh (case study 8). The main problem seems to be capturing the largely donor supported interventions within the local legal frameworks, as well as generating the political commitment to take over the budgets. In Rwanda the Global Fund provides partial funding for social support interventions based upon the existing legal framework, initially put into place by the government (case study 9), and there is commitment for taking over the budget again after the Global Fund is phased out.

Lessons Learned

As elegantly stated in the WHO/AFRO guide on best practices, ^{Error! Bookmark not defined.} "the documentation and dissemination of best practices provides opportunities for acquiring knowledge about what works and to continue learning about how to improve and adapt strategies and activities through feedback, reflection and analysis in order to implement larger-scale, sustained, and more effective interventions." From the information on the ten practices collected from the different partners we have learned valuable lessons that are useful for future scale-up of effective and sustainable social support models.

Effectiveness: The best practices identified here strongly suggest that psycho-socio-economic support interventions can add significant value to TB control through improvements in treatment success rates and reductions in patient suffering. Delivery of social support to TB patients requires collaboration through multidisciplinary teams, quite often in close collaboration with or organized by people outside of the NTP. Several programs considered cash payments an effective tool to promote adherence.

Clear procedures for identifying patients' needs through PCAs are likely to help effective targeting of social support resources and promote accountability. Well-designed social support systems can be a viable and affordable alternative to the compulsory treatment of non-adherent patients, without the human rights violations and risk of TB transmission commonly associated with compulsory treatment.

Sustainability: Recognition by health sector leaders of the difficulties faced by patients to adhere to treatment is paramount for the adoption of social support interventions. Fundamental to the adoption, high-performance and sustainability of social support interventions are the existence (or development) of conducive legal frameworks, including both psycho-emotional and socio-economic support components, and collaboration between the MoH (NTP) and those responsible for social protection schemes in other government sectors.

Possibility of scale-up: The best practices identified here show that social support interventions are feasible and scalable, even in low income countries. Political commitment was found to be essential for nationwide scale-up of social support interventions: in countries where political commitment was generated and translated into support for legal frameworks and budgets from government or combined government and donor sources, projects have shown to be scalable.

Conclusions and Recommendations

Comprehensive psycho-socio-economic support interventions are effective and feasible in both high and low income settings.

NTPs and their partners are advised to embed all elements of social support interventions into the legal framework and to integrate (partial) government funding of the interventions into the design right from the start.

Countries are encouraged to explore the use of conditional cash transfers and microfinance. These forms of social support may be an effective way to alleviate poverty amongst TB patients and people in general.

NTPs and their partners are recommended to perform more systematic data collection for psycho-socio-economic support to monitor implementation and evaluate effectiveness and efficiency and to enable further assessment of equity and scalability of the different approaches. Special attention should be paid to the evaluation of the reduction of cost burden, which is an explicit element of the End TB strategy. Evaluation information should be used to show accountability and increase political commitment.

The WHO Global TB program is advised to work with partners to make specific recommendations on the use of social support interventions for TB care and control; propose a mechanism and indicators for countries to manage and monitor implementation; and to promote the research needed to improve the understanding of the role of social support in TB care and control and increase its impact.

The Stop TB Partnership is recommended to strongly advocate for donors, countries, researchers technical partners to incorporate social support interventions into their respective agendas to address the catastrophic costs patients incur, and mitigate the stigma and discrimination suffered by patients.

The Global Fund and other major donors are recommended to promote the implementation of social support interventions through sustainable funding mechanisms.

Table 1. Summary of main findings in identified initiatives on social support for TB and MDR-TB patients

Initiative	Social support			Legal framework	Pilot / country-wide	Partnership	Evaluation/ reported impact	Funding	Scalability
	Education/ information	psychological	Material/ economic						
Former MDR-TB patients involved in communication training - Indonesia	Yes	Yes -	None	-	pilot	Ex-patients	Preliminary results indicate higher treatment initiation and less loss-to-follow-up	USAID (FHI 360, KNCV, WHO); MoH; GF	NTP integrated this intervention into National PMDT training modules. Lack of trainer capacity is an obstacle for scale-up
Social support in Kazakhstan	yes	Yes	CCT; food basket; hygiene packs; free services	Sick leave allowance; disability allowance	pilot	NGOs, ex-patients and local NGOs	Improved treatment adherence	Government-funded/ GF in small proportion of patients	Included into national legal framework and NSP (2014-2020)
Social support in Latvia	yes	yes	Transport and food vouchers;	State social disability allowance	Partly national, partly local (Riga)	-	No formal evaluation; treatment outcomes and declining MDR-TB rates are compelling	Government funded	Legal framework is present, government budget is available and based on number of TB patients in the country
Social support for MDR-TB patients in Namibia	Yes; income generating projects	yes	Non-CCT; food basket;	Sick leave allowance; disability allowance	Country-wide	NGOs; community;	No formal evaluation; reduced loss-to-follow-up	Social protection grants (state); food (GF); training (USAID); and NGOs	Sustainable as the government finances basic support
Fund for special needs in The Netherlands	yes	yes	Non-CCT; food and transport vouchers	Generic social disability grant / social security fund	Country-wide	-	No evaluation; perceived to be effective	Funded by national charity lottery	Has been in place at national level since 1979

Patient-Centered Approach package (Cambodia, Indonesia, Mozambique, Nigeria and Zambia)	yes	-	-	Universal health coverage	pilot	NGOs; NTP	No evaluation; perceived to be useful	USAID	Pending political commitment in respective countries
Social support for MDR-TB patients in Peru	yes	yes	CCT; food basket;	-	pilot	NGOs; central government	No evaluation; perceived to be effective	GF and NGO	Pending political commitment ; no regulatory framework for psycho-socio-economic support
Sputnik program in Russia (Voronezh)	yes	yes	Food basket;	Local decrees	pilot	NGOs; local government; community	Improved treatment adherence after inclusion in project	Eli Lilly Foundation; NGO	Pending political commitment
Social support for MDR-TB patients in Rwanda	yes	yes	food basket, hygiene packs; transport vouchers, housing if needed,	Yes	-	-	No evaluation, but treatment outcomes reported are compelling	Government and GF; government committed to keep program after GF phases out	National implementation in place already
Social support for MDR-TB patients in Tajikistan	probable	yes	Waivers on utilities' bill and taxes; non-CCT; food baskets; hygiene packs	unclear	Pilot	Community and religious leaders;	No evaluation yet	Local government and USAID	National legal framework for inclusion of TB treatment as eligibility criterion for sick leave allowance was developed and approved

Annexes

1. Best Practice Data Collection Questionnaire

“Best Practice” Description Form

Please fill out this form by typing your responses in the appropriate box

Country:	Organization:
Name/ Surname:	Title:
Postal address:	Email address:
Telephone number:	Names and addresses of contributors:
1. Title	
This should be concise and reflect the practice being documented.	
2. Introduction	
This should provide the context and justification for the practice and address the following issues	
a. What is the problem being addressed?	
b. Which populations are affected by the problem?	
c. How is the problem impacting on the population?	
d. What are the objectives of the practice?	
3. Description of the implementation of the Best Practice	
a. Does the best practice involve psycho-emotional and/or socio-economic support?	Psycho-emotional support: yes/no Socio-economic support: yes/no
<i>Implementation of psycho-emotional support (if applicable)</i>	
b. Please give a short description of the psycho-emotional support implemented (e.g. individual counseling, group counseling, etc.) and how provision of this support is organized?	
c. Which TB patient groups are eligible for psycho-emotional support (selection criteria type of patient, at what stage of treatment, etc.)?	
d. Did the practice include a change in eligibility criteria? If yes, also describe the previous criteria/practices.	
e. When did each type of psycho-emotional support commence and	

end (during diagnosis and treatment)?	
Implementation of socio-economic support (if applicable)	
f. Please give a short description of the socio-economic support implemented (e.g. cash, food, vouchers, etc.) and how provision of this support is organized?	
g. Which TB patient groups are eligible for socio-economic support (selection criteria type of patient, at what stage of treatment, etc.)?	
h. Did the practice include a change in eligibility criteria? If yes, also describe the previous criteria/practices.	
i. When did each type of socio-economic support commence and end (during diagnosis and treatment)?	
j. What was the value of each type of support, per patient?	
k. What patient costs were not covered by the economic support?	
l. If available, what was the average and range of household and/or patient incomes before and after becoming ill with TB?	
Details of Best Practice activities (refer to earlier answers if applicable)	
m. What are the main activities carried out to implement the patient support best practice?	
n. Where and since when were the best practice support activities carried out? (give also end date if applicable)	
o. Who are the key implementers (e.g. nurses, social workers, psychologists, etc.) and collaborating organizations of the best practice?	
p. How are qualifications and skills of staff involved in coordinating and delivering the patient support practice ensured (e.g. training, etc.)?	
q. What is the level of the population being addressed (community, district, regional within a country, national, inter-country)?	
r. What are conditions for (further) scaling it up? Conditions can relate to resources, political buy-in, demands, etc.	
s. Is the community involved in the practice? If yes, how (e.g. community health workers, community volunteers, etc.)?	

t. Is there a regulatory framework to support the patient support practice? If yes, was it introduced specifically for this practice?	
u. Is the regulatory framework specifically for TB patients or also for other patients?	
v. Does the practice include support for risk groups (e.g. prisoners, migrants, homeless, Drug/alcohol addicts, PLWHA)? If yes, what groups and how?	
w. Are childhood TB patients included in this practice? Are there special regulations for them?	
4. Situational description	
a. How many TB patients are there in total (annually)? Please provide details per year, for last 1-3 years.	
b. How many eligible TB patients are there (annually)?	
c. How many TB patients receive support within the described Best Practice (annually)?	
d. In the last year, in the area where the best practice is implemented, what was (1): the number of persons with active TB resistant to at least rifampicin? (2): the number of patients that received a diagnosis of rifampicin resistance? (3): the number of patients who haven't started treatment (yet) for rifampicin resistant TB? (4): Of those who did start treatment for rifampicin resistant TB, how many were lost to follow-up for at least 2 months?	(1): (2): (3): (4):
e. Are any other patients (non-TB patients) also eligible for the practice? Who and how many are they?	
5. Ambulatory care. <i>As in many countries (MDR) TB patients are hospitalized during (part of the) treatment, please provide information on how ambulatory care is organized in your best practice setting.</i>	
a. Are there criteria for eligibility for (MDR) TB patients to start and/or continue treatment on an outpatient (ambulatory) basis?? If yes, what are they? Did the practice include a change in criteria? If yes, also describe the previous criteria/practices.	
b. How is ambulatory care for MDR-TB patients organized? e.g. is DOT integrated in primary health care or not, is home-based care available, etc. Are patients given an option to	

choose on how ambulatory care is organized?	
c. How is community transmission prevented during ambulatory care?	
d. Under the best practice, what patient support is provided during inpatient care and what patient support is provided during ambulatory care?	
6. Financing of the practice	
a. How is the practice financed? Through government and/or donors? Through the health system or through social services?	
b. Who is the legal budget holder (name budget holder per support, if different)?	
c. Is financing per donor continuous over time?	
d. Who decides on allocation of the budget(s)?	
e. What was the annual budget (per budget holder) in most recent year for which data are available?	
f. What is the number of patients covered with this budget in this year?	
7. Results of the Practice – Outputs and Outcomes	
a. Is there a routine M&E framework to monitor implementation and results of the practice? If yes, what indicators are used?	
b. Was the practice ever evaluated on outputs and outcomes? If yes, by whom and what were the concrete results achieved in terms of outputs and outcomes?	
c. Have the rates of diagnosis-seeking, treatment seeking, treatment adherence and treatment completion improved since the measures were introduced? Please provide at least treatment outcomes including default before and after implementation of the practice, when available. If available, please also include data on treatment adherence (number and percentage of missed dosages before and after).	
d. Was the practice scaled up within or outside the original patient group or geographical area (e.g. based on pilot results)?	
10. Lessons Learned	
a. What worked really well? – what facilitated this?	
b. What challenges had to be overcome? – how was this	

achieved?	
c. What did not work – why did it not work?	
11. Conclusion	
a. How have the results benefited the population?	
b. Why may the intervention be considered a “Best Practice”?	
c. Recommendations for those intending to adopt the documented “Best Practice” or how it can help people working on the same issue(s).	
12. Further Reading Provide a list of references (not more than six) that give additional information on the “Best Practice” for those who may be interested in how the results have benefited the population.	

Thank you!

Who can we approach in case we have questions for clarification? Please provide contact details (name, organization and email address) if different from details provided on top of this form:

Description of best practices are being compiled within the USAID funded TB CARE project.

Do you give **permission** for inclusion of a description of the best practice described in this document under this project? **YES** **NO** (please check appropriate box)

If **YES**, would you like us to **send you the text** summarizing the best practice described in this document before we report the results? **YES** **NO** (please check appropriate box)

If you have **questions** while filling out the description framework, please contact the relevant person in your organization (who distributed this framework). If this is not possible, contact Susan van den Hof (KNCV Tuberculosis Foundation, email: susan.vandenhof@kncvtbc.org).



USAID
FROM THE AMERICAN PEOPLE

TB CARE I

TB CARE II

2. Contact Details Per Initiative

Initiative	Organization	Contact person
Indonesia	FHI 360 Indonesia	Chawalit Natpratan cnatpratan@fhi360.org
Kazakhstan	KNCV Tuberculosis Foundation, Representative Office in Central Asia, Almaty, Kazakhstan	Gulnara Kaliakbarova gulnara.kaliakbarova@kncvtbc.org
Latvia	National TB program, Latvia	Liga Kuksa Liga.Kuksa@aslimnica.lv
Namibia	Ministry of Health & Social Services; KNCV Tuberculosis Foundation	Nunurai Ruswa nunurai.ruswa@kncvtbc.org
Netherlands	KNCV Tuberculosis Foundation	Niesje Jansen niesje.jansen@kncvtbc.org
Patient-Centered Approach	KNCV Tuberculosis Foundation	Sara Massaut sara.massaut@kncvtbc.org
Tajikistan	KNCV Tuberculosis Foundation, Branch Office in Tajikistan	Mavluda Makhmudova mavluda.makhmudova@kncvtbc.org
Perú	Socios En Salud Sucursal Perú/ PIH Peru	Leonid Lecca llecca_ses@pih.org
Russian Federation (Veronezh)	Partners in Health	Oksana Ponomarenko oksana@pih.ru
Rwanda	Rwanda Biomedical Centre/TB Division	Yves Habimana-Mucyo yves.mucyo@rbc.gov.rw

References

- ¹ Tanimura T, Jaramillo E, Weil D, Raviglione M, Lönnroth K. Financial burden for tuberculosis patients in low- and middle-income countries: a systematic review. *Eur Respir J*. 2014 Jun; 43(6):1763-75.
- ² TB CARE I patient cost pilot report in Ethiopia, Indonesia, Kazakhstan. Available at: <http://www.tbcare1.org/publications/toolbox/costing/> (accessed 10 October 2014)
- ³ Global tuberculosis report 2013. Geneva: World Health Organization; 2013 (WHO/HTM/TB/2013.11; http://www.who.int/tb/publications/global_report/en/, accessed 27 March 2014).
- ⁴ Volmink J, Garner P. Interventions for promoting adherence to tuberculosis management. *Cochrane Database Syst Rev*. 2000;(4):CD000010.
- ⁵ Munro SA, Lewin SA, Smith HJ, Engel ME, Fretheim A, et al. (2007) Patient adherence to tuberculosis treatment: a systematic review of qualitative research. *PLoS Med* 4: e238.
- ⁶ M'imunya JM, Kredo T, Volmink J. Patient education and counselling for promoting adherence to treatment for tuberculosis. *Cochrane Database Syst Rev*. 2012 May 16;5:CD006591.
- ⁷ Lutge EE, Wiysonge CS, Knight SE, Volmink J. Material incentives and enablers in the management of tuberculosis. *Cochrane Database Syst Rev*. 2012 Jan18;1:CD007952
- ⁸ Fitzpatrick C, Floyd K. A systematic review of the cost and cost effectiveness of treatment for multiMDRug-resistant tuberculosis. *Pharmacoeconomics*. 2012 Jan; 30(1):63-80.
- ⁹ Bassili A, Fitzpatrick C, Qadeer E, Fatima R, Floyd K, Jaramillo E. A systematic review of the effectiveness of hospital- and ambulatory-based management of multiMDRug-resistant tuberculosis. *Am J Trop Med Hyg*. 2013 Aug; 89(2):271-80.
- ¹⁰ Health as Communication Nexus: A Service-Learning Approach. Marifran Mattson, Jennifer Gibb Hall Kendall Hunt Publishing Company, 2011
- ¹¹ Taylor SE. Social support: A Review. In: *The handbook of health psychology*. Friedman MS, editor. New York: Oxford University Press; 2011:189–214.
- ¹² <http://www.bitpipe.com/tlist/best-practices.html> (accessed 10 October 2014)
- ¹³ Guide for Documenting and Sharing “Best Practices” in Health Programs. WHO AFRO, Brazzaville, 2008.
- ¹⁴ Best practices in prevention, control and care for drug-resistant tuberculosis. A resource for the continued implementation of the Consolidated Action Plan to Prevent and Combat Multidrug- and Extensively drug-Resistant Tuberculosis in the WHO European Region, 2011–2015. WHO EURO, Copenhagen, 2013.
- ¹⁵ Bassett L, Bianco G. Control and accountability in conditional cash transfer programs in Latin America and the Caribbean: key topics and areas for further improvement. Washington, DC: World Bank, 2011.
- ¹⁶ Boccia D, Hargreaves J, Lönnroth K, Jaramillo E, Weiss J, Uplekar M, Porter JDH, Evans CA (2011). Cash transfer and microfinance interventions for tuberculosis control: review of the impact evidence and policy implications. *Int J Tuberc Lung Dis* 15: S37-S49.