PROVIDING COMPREHENSIVE, PATIENT-CENTERED CARE

A Conceptual Framework for Social Support of TB Patients

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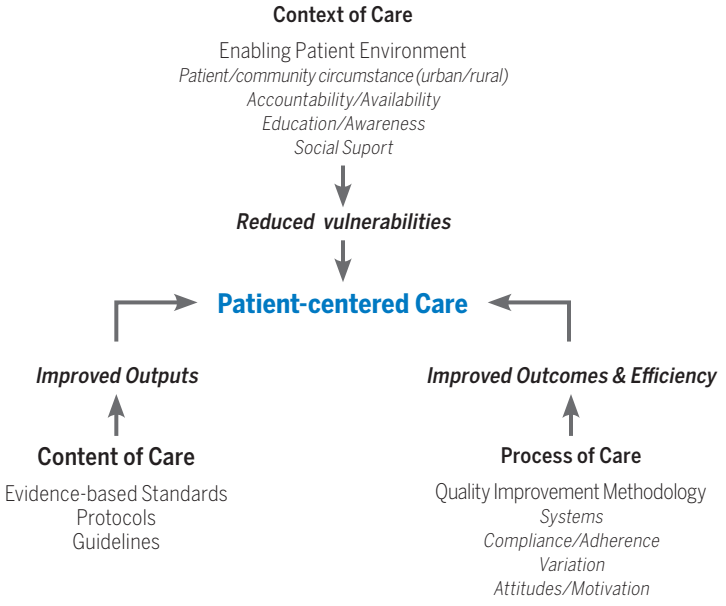
Introduction

Tuberculosis (TB) disease occurs most often within the context of economic and social vulnerabilities, and patients receiving TB treatment frequently experience other psychological, social and economic problems that may interfere with their ability to complete treatment. An episode of TB may further exacerbate poverty or reduce a patient or family's economic and social wellbeing, and even if cure is attained, the experience of TB can reinforce health and social disparities and increase the risk of reinfection. The effect of TB can be especially profound for patients who already experience vulnerabilities, including migrants, the homeless, prisoners, people living with HIV infection, patients with substance abuse problems, social/cultural minorities, and other marginalized groups.

In preparing this document, we recognize that the provision of high quality care for TB, TB/HIV and multidrug-resistant (MDR) TB patients requires effectively addressing the social conditions that underlie the occurrence of TB disease and can prevent positive outcomes or expose a TB patient to significant economic or social risk. Increasingly, our programmatic experience has demonstrated that in addition to addressing the process and content of clinical care, in order to provide truly patient-centered care, it is also necessary to address the context in which the patient experiences illness and receives care. The need to move beyond

Figure 1. Multi-dimensional Strategies for Improving Patient Outcomes



successes in clinical service delivery to better address TB patients' holistic health and social needs is becoming increasingly apparent. The post-2015 Global TB Strategy, endorsed by the World Health Assembly in May 2014 includes, targets around the reduction of catastrophic costs by TB patients and calls for bold policies and programs around *"social protection, poverty alleviation and actions on other determinants of tuberculosis."*

The objective of this document is to provide a framework for URC projects involved in TB, TB/HIV and MDR TB to better plan, manage, and coordinate delivery of social support and social protection services for TB patients. This guide includes lessons from existing TB social support programs, including those supported by URC. Building on these lessons, this guide seeks to articulate a minimum package of effective social support and social protection services, emanating from discussions around the purpose and need for different social support components, and potential partnerships with existing service providers. It is evident that patients require a different set of services depending on their context (including their disease profile, economic status, age, sex, specific social conditions, etc.). Therefore, this framework is not designed to be prescriptive, but rather to provide guidance to programs to review, design, and monitor social support packages to advance their TB programmatic objectives.

Why should TB programs be concerned with social support/social protection?

- **To find the missing 3 million:** Economic barriers are a leading reason why TB patients do not seek timely, effective diagnoses from qualified providers.
- **To improve treatment outcomes:** Ensuring patients have the adequate, holistic support they need to complete treatment is the bed-rock of patient-centered care.
- **To prevent future cases and contribute to a society free of TB:** When TB no longer leads to more vulnerability and poverty, fewer people will be at risk of re-infection.

Social Determinants of Health for TB Patients

As public health professionals, we know that public health achievements largely depend on actions outside the health care sector (Commission on Social Determinants for Health, 2008). TB is a leading example of just such a social disease, hence current TB control strategies need to be complemented with efforts to address the psychosocial and economical needs of TB patients. Failing to address the social and economic conditions that create vulnerability to TB will directly impact our ability to effectively combat the disease. In the United States and Western Europe, declines in TB rates starting in the middle of the 20th century were closely linked to improvements in social, environmental, and economic conditions of communities. Indeed, reductions in TB incidence outpaced improvements in treatment, leading to the conclusion that poverty reduction is one of the single most important factors in reducing TB incidence.

Providing diagnosis and treatment alone do not guarantee that the TB patient will be cured and remain healthy. We know that a battery of factors, when combined together, affect the health of individuals and communities (**Figure 2**).

Figure 2. Influences on Health-seeking Behavior

Many factors affect a TB patient's treatment outcomes and overall experience of care. These include:

- Personal knowledge about TB, motivation to adhere to treatment, and coping mechanisms to deal with side effects.
- Social and cultural support systems, including the direct support a TB patient receives from their family and friends as well as social norms that prescribe certain behaviors based on the TB patient's sex, age, and other categories/labels.
- Comprehensive health services, including access to and use of services to prevent and treat disease, such as referrals to the treatment of co-morbidities such as HIV or diabetes.
- Financial and economic security, including retention of employment and income.
- Physical environment requirements including transportation and housing costs.
- Supportive community resources such as education, security/police, etc.

Failure to account for any of the above factors may result in delays in seeking TB care or treatment, barriers to care, and may negatively impact treatment outcomes. Thus, ensuring the availability of free TB diagnostics and treatment services is not sufficient to ensure that patients will access these services and complete their treatment regimens. Social support of TB patients helps to helps to mitigate existing barriers in receiving TB care. Social support can be defined as the "process of interaction in relationships which improves coping, esteem, belonging, and competence through actual or perceived exchanges of physical or psychosocial resources" (Gottlieb 2000).

A Conceptual Framework for Social Support

As previously mentioned, the new Global TB Strategy calls for "bold policy supportive systems" as a pillar of TB control efforts for all high burden countries. Therefore, a critical component of any TB control strategy must be social protection of TB patients, backed by a goal of reducing financial hardship experienced by TB patients. However, currently there is little consensus on what comprises a social protection package for TB patients, their families and communities, or who is responsible for providing these services. Similarly, there are still relatively few programmatic best practice examples of how social support services can be organized and managed for TB patients.

The following sections outline several of the key areas of social support/social protection that have begun to emerge in different settings. It is important to note that almost no country is as yet providing the comprehensive package of services, nor may all services be equally necessary for TB patients in all settings. There is also some overlap between the objective and method of different services listed. Nevertheless, the categories discussed below are meant to provide an illustrative list of modes and types of social support that are currently implemented or debated in high burden countries. These are organized into the following basic categories:

1. Services to mitigate the financial impact of TB treatment;
2. Direct provision of key treatment support services (i.e., transport, nutrition and housing);
3. Psychosocial, counselling and mental health services;
4. Linkages and networks with other community social and development services (i.e., micro-finance and livelihood development services); and
5. Providing support for caregivers of TB patients.

Financial Support Packages

The financial burden of TB for a patient and his/her family impacts their overall economic welfare as well as their ability to maintain treatment until cure. Even when diagnosis and treatment services are provided free of charge, additional costs related to accessing and maintaining treatment, such as transport, food, and upkeep of both the patient and guardian, have to be met. On average, TB patients in low- and middle-income countries face medical expenses, costs for seeking/staying in care, and income loss equivalent to more than 50% of his or her annual income (WHO).

In general, patient financial support systems aim to enable patients to access treatment without negative financial consequences and to avert further slide into poverty by protecting and building their financial, physical and human capital assets. Some examples of direct economic assistance are program incentives, transport reimbursements, and treatment allowances. Cash transfers can be unconditional – without any type of obligation to be met, or conditional – with some behavioral requirements like treatment adherence. Financial support may be provided through routine payments to a patient or their caregiver, in cash or through cash transfer systems.

EXAMPLE

Mobile Cash Transfers for MDR TB Patients in Bangladesh

Through the TB CARE II project, MDR TB patients receive allowances – small monetary payments – to help them buy extra food to support good nutrition during their treatment. TB CARE II, in partnership with Dutch-Bangla Bank, Ltd. (DBBL), sends monthly allowances directly to patients and providers via mobile banking services. The mobile banking system has made life easier not only for the patients and providers, who can now access their funds with a quick visit to an ATM or banking agent.

With the adoption of formal Universal Health Coverage (UHC) policies in many high burden TB countries, health insurance programs have come to form a critical part of social protection. However, UHC's three main pillars such as coverage, access and use, and quality of services still have some limitations, creating gaps in TB services. Shrinking healthcare budgets, inefficient delivery systems, poor service quality in developing countries oftentimes make "free" health care delivery system impossible, and in practice, are never free. Moreover, UHC in different countries have some restrictions such as coverage of patients only from the formal sector, requirements of possession of IDs, and limited coverage of MDR TB, which can jeopardize the access of the most vulnerable groups to TB care. Many countries do not have sufficient private health

EXAMPLE

Village Banking TB Initiative in Cambodia

In 1995 the Cambodia Health Committee (CHC) undertook a successful village banking initiative to support TB patients and their families and to partner microfinance with TB cure and adherence. CHC provided loans for small income-generating projects in Svay Rieng and Kampot provinces linked to its community-based TB programs. Profits from the village banking program were used further to fund village health agents, who identifies TB patients, as well as delivered basic health education. The program reached more than 13,000 people across seven provinces in Cambodia, achieving very high payback rates among TB patients participating in the program with 100% adherence to TB medicines. The initiative further grew onto an expansive community- based health insurance program, which entitles members to health care coverage for all medical costs for services incurred at contracted health centers and referral hospitals. Moreover, it covers non- medical costs such as emergency transportation and funeral expense should a member pass away.

insurance programs, or their schemes do not cover TB diagnosis and treatment. Developing a role of insurance providers in TB care, with mechanisms to provide direct benefits to TB patients would be an important agenda for ensuring access to health services.

In some places, Community-Based Health Insurance (CBHI) schemes are available to and may assist patients to defray the expenditures related to accessing and adhering to treatment. CBHI schemes are often local initiatives that build on traditional coping mechanisms to provide small health insurance products specially designed to meet the needs of low income households. They are typically voluntary schemes, and are based on concepts of mutual aid and social solidarity.

Treatment Support Services

As an alternative to or in conjunction with direct financial assistance to patients, indirect economic assistance can be provided through the distribution of food parcels, food or travel vouchers, or other goods aimed at making it easier for patients to receive treatment. Different examples of what are variously called enablers or treatment support/ motivational packages given by various program implementers to TB patients on treatment may target:

1. **Transportation:** Bus tokens, passes, taxi vouchers, (may be offered in addition to transportation reimbursement with cash transfers described above). Every effort should be made to consolidate the trips required every month of TB treatment. Patients should be supported according to individual needs considering geographic location and method of transport.
2. **Stable housing:** Shelters, rent assistance, other housing programs (churches, rehabilitation centers, etc.). Some TB patients might be needed in temporary accommodation if homeless, have very difficult family situations, patients who are too ill to go home, but too well to be in the hospital, those who live in very remote areas.
3. **Other material needs:** Hygiene kits, clothing and/or footwear, newspapers, board games, or other household goods.

Five Key Principles of Nutritional Care and Support for TB Patients

(WHO Nutrition Advisory Group, 2013)

Key principle 1: All people with active TB should receive TB diagnosis, treatment and care according to WHO guidelines and international standards of care.

Key principle 2: An adequate diet, containing all essential macro- and micronutrients, is necessary for the well- being and health of all people, including those with TB infection or disease.

Key principle 3: Because of the clear bidirectional causal link between under nutrition and active TB, nutrition screening, assessment and management are integral components of TB treatment and care.

Key principle 4: Poverty and food insecurity are both causes and consequences of TB, and those involved in TB care therefore play an important role in recognizing and addressing these wider socioeconomic issues.

Key principle 5: TB is commonly accompanied by comorbidities such as HIV, diabetes mellitus, smoking and alcohol or substance misuse, which have their own nutritional implications, and these should be fully considered during nutrition screening, assessment and counseling.

4. **Nutritional needs:** Under-nutrition is itself a risk factor for TB, and can also be as a consequence of TB. There is as yet little evidence showing that additional nutrition support improves TB-specific outcomes, but low body mass index as well as lack of adequate weight gain during TB treatment are associated with an increased risk of TB relapse and death. The basic recommendations to address nutritional needs of TB patients is discussed below. Food packages should be designed according to the World Food Program guidelines for HIV patients starting ART and TB patients starting treatment, and include: cereals (maize, rice, sorghum, millets, etc.); pulses (peas, beans, lentils, etc.); oil; sugar, salt; animal products (canned fish, beef and cheese, dried fish); and dried skimmed milk.

Among the basic recommendations to address nutritional needs of TB patients include:

1. **Conducting an initial nutrition assessment** of TB patients with further monitoring;
2. **Providing ongoing counseling** for patients on their nutritional status;
3. **Management of severe acute malnutrition** should be treated according to national guidelines and WHO recommendations;
4. **Management of moderate under nutrition** for TB patients who fail to regain normal Body Mass Index (BMI) after two months of TB treatment or appear to lose weight during TB treatment should be evaluated for a proper treatment adherence and other comorbidities. If indicated, these patients should be provided with locally available nutrient- rich or fortified supplementary foods. Special categories of TB patients such as children who are less than 5 years of age should be managed as any other children with moderate under nutrition. Pregnant women with active TB, patients with MDR TB should be provided with locally available nutrient- rich or fortified supplementary foods.

EXAMPLE

A Package of Patient Support Incentives in Russia

One example of patient incentives is from three Russian oblasts (Ivanovo, Orel, and Vladimir). Since 2000 TB outpatients were given a combination of food packages, hot meals, transport reimbursement, hygiene packages, and clothing based on their continued clinic attendance and observed treatment. Patients were eligible to receive incentives if they do not interrupt their treatment and denied when they missed one week or more of TB treatment intake. This intervention helped with a decrease of default rate, i.e. default rate in Orel and Vladimir were between 2 and 6% in 2004, down from between 15 and 20 percent when the program began in 1999.

5. **Micronutrient supplementation** for all pregnant women as well as lactating women with active TB. These women should be provided with iron and folic acid and other vitamin and minerals to complement their maternal micronutrient needs. In situations when calcium intake is low, calcium supplementation is recommended as part of antenatal care.

EXAMPLE

Promoting Treatment Adherence Through Food Incentives in Kyrgyz Prisons

Economical support as an incentive mechanism is widely used in TB control program in the prison settings of the Kyrgyz Republic. Inmates on TB treatment receive motivational food packages in a weekly basis based on their adherence during that week. Such social support packages are supported by international partners, mainly by the International Committee of the Red Cross, Doctors without Borders.

Psychosocial Support and Mental Health

TB is often associated with substantial upheaval in a patient's life, and can have profound psychological and social effects. The multiple burdens a patient and their family may experience relate to stigma, isolation, feelings of helplessness, familial emotional trauma, medication side effects, and other reactions to the disclosure of the diagnosis.

Unfortunately, stigma continues to play a big role in the experience of TB illness. This issue may arise especially among women in some communities, where they not only lack an access to health care services, but may also suffer from social isolation, rejection from their families, especially their husbands, and harassment as a result of TB.

The Interplay Between TB and Mental Illness

A review of existing literature related to mental health and TB conducted in 2013 identified rates of mental illness of up to 70% in TB patients. TB medications known to have significant adverse psychiatric effects include cycloserine, and drugs such as rifampicin have been seen to reduce the effectiveness of anti-psychotic medications. TB providers need to be aware of the possibility of encountering patients with undiagnosed mental health disorders, and of the possible impact of TB drugs on the mental health of patients (Doherty AM, Kelly et al).

In more severe cases, a patient may experience psychiatric issues such as depression or anxiety due to underlying conditions, factors related to their mental state during treatment, and/or drug side effects. Conversely, patients with existing mental health disorders who get sick with TB may require specific treatment interventions. TB and mental illness have many common risk factors in some settings (i.e. homelessness, substance abuse, and the presence of significant co-morbidities such as HIV).

Psychosocial support is a crucial component of TB treatment. Adequate counselling, psychological support, and referral to mental health services facilitate not only completion of complicated treatment, especially in cases of MDR TB, but also support the mental wellbeing and development of coping mechanisms for patients.

Several components of psychosocial support are used for TB patients, including:

- Individual counseling or case work;
- Support groups or self-help groups;
- Community engagement to support TB patients; and

- Provider training around interpersonal counselling and identification of mental health needs.

Some TB control programs use other types of psychosocial support like recreational excursions, symbolic celebrations, and family workshops which could be considered as part of support groups and social mobilization. Existing counselling or support group services developed in conjunction with other health programs or sectors, such as HIV programs in countries with high infection rates, can be leveraged as examples or systems which could be expanded.

EXAMPLE

Community-based Support Groups in Bihar, India

The community- based groups led by women leaders were created in Bihar, India with a support of the Axshya Project. Women in villages meet monthly and discuss various concerning issues, including TB. They encourage women in villages to get tested for TB if they are symptomatic, and to seek treatment.

EXAMPLE

TB Clubs in Malawi

In Malawi, within the Mwanza AIDS Support Organization (MWASO), 3 to 10 non- infectious patients and former TB patients form "TB clubs". They main purpose of creating such groups is to support each other by attending outpatient visits together, support each other with treatment adherence, identify possible adverse drug reactions in other members, etc.

Linkages with Other Treatment, Social Support and Development Services

Unfortunately, a patient often experiences TB disease in connection with or along with other health and social issues. Patients may have other co-morbidities such as HIV, diabetes mellitus, chronic lung diseases, viral hepatitis, STIs, etc., or may suffer from substance abuse, or have socio-economic challenges which create inadequate nutrition. Mechanisms for delivery of integrated tuberculosis patient care and other services need to be established not only to address medical issues, but also keep in mind concurrent social care and support needs. Implementing integrated services is intended to increase access to TB services, improve the timeliness of service delivery as well as increase the effectiveness of efforts to prevent infectious diseases and disorders that share common risk factors, behaviors, and social determinants.

Conducting Mental Health Screening for TB Patients

A programmatic intervention may include introducing a simple mental health screening questionnaires for providers of high risk patients or for patients exhibiting potential mental health issues. Referrals for counselling or other mental health services may be provided, if available. *Example: Mental Health Assessment Tool for TB Patients: Heartland TB Center.*

Networking care for TB patients at the community level: Comprehensive, integrated models of care can be reached by provision of multiple services at a single venue or through coordination of referrals for services delivered at multiple venues. Outreach programs, HIV counseling, access to harm reduction activities and opioid- substitution therapy are some of the examples of networked care, especially for patients at the community level. As decentralized treatment programs for TB and MDR TB expand, coordination between community-based health and social services is important to leverage resources, provide adequate support to patients and their care givers, avoid duplication and provide patient-centered care.

Income generation: On average, 60% of the total TB economic burden can be attributed to income loss (T. Tanimura et al). As discussed above, providing financial support to defray the costs of TB treatment is critical, but loss of income as a result either of loss of employment due to illness or time away from work to attend the clinic can also be highly detrimental to a patient or family's economic wellbeing. The benefits of income support to the individual and his family may not be immediately quantifiable, as economic returns occur a later point of time and depend on many external factors, but can impact positively on self- sufficiency and income-generation.

While TB programs and TB providers may not be in a position to directly support income generation for TB patients, some steps that may be considered include:

- Coordinating treatment and monitoring appointments around a patient's work schedule;
- DOTS provider may assist the patient to discuss their treatment with their employer and may provide counselling to dispel myths or stereotypes;
- Coordination or referrals for TB patients to other income generation programs such as microcredit loans, vocational training/training programs, or microenterprise activities;
- Conducting outreach with civil society to identify community services which might benefit TB patients;
- Creation of home banks as an income generating activity (IGA) for affected families.

EXAMPLE

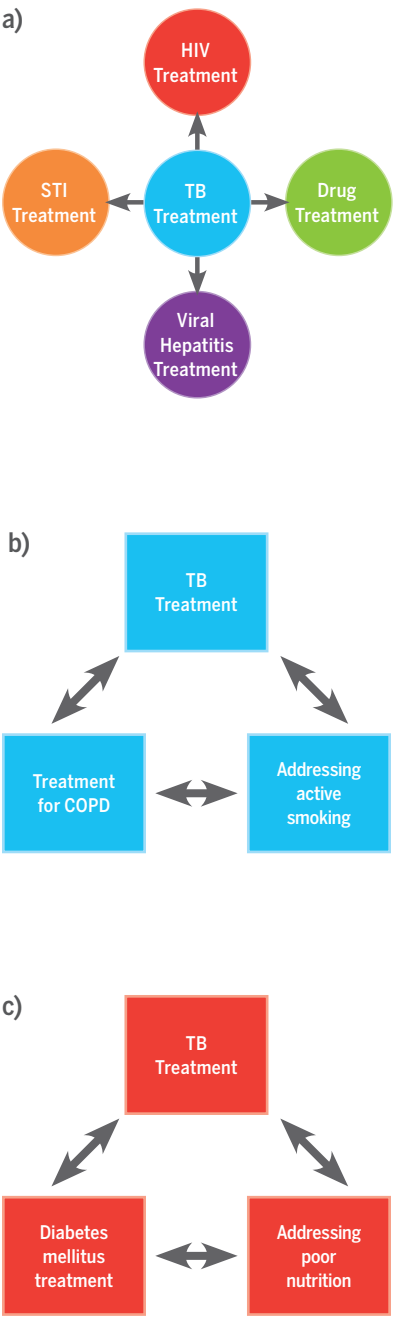
The Innovative Socio-Economic Interventions Against Tuberculosis (ISIAT)

This project was implemented in Lima, Peru covering 2078 people in 311 households of newly diagnosed TB patients for up to 34 months. The activities included microcredit loans, vocational training and microenterprise activities such as raising animals (rabbits and chicken) and home- based manufacturing (e.g. foodstuffs, recycling, greeting cards, knitting, weaving, jewelers, toy and handicraft manufacture). These interventions were designed to diminish economic barriers to TB care and appeared to considerably increase uptake of the TB control services that the National Tuberculosis Program offers free of charge with social and nutritional support. This project provided evidence that socio- economic interventions can positively impact TB control activities.

The WHO Engage Approach

The Engage TB approach by WHO focuses on integrating community based TB activities into the work of NGOs and other civil society organizations has a greater role on supporting economic independence. Network and collaboration with NGOs to empower TB patients, to make linkages to employment opportunities, vocational training is essential. Above all, WHO is developing a post- 2015 Global TB Strategy, which considers a high priority for the need for all countries not only to progress towards universal health coverage to ensure "universal access to needed health services without financial hardship in paying for them", but also social protection mechanisms for "income replacements and social support in the event of illness".

Figure 3. Examples of integrated services



The benefits of addressing a TB patient's need to ensure that a regular income is maintained during treatment, in addition to helping reduce the likelihood of catastrophic expenditures and negative financial impact, can also to improve mental health and the decrease the likelihood that a patient will interrupt treatment when they start feeling better in favor of work opportunities.

EXAMPLE

MUKIKUTE Income Generation in Tanzania

An NGO in Tanzania MUKIKUTE has created different projects for income generation, these included: a drama club, which has been used for community sensitization as well as it usually lent out in different occasions, making "tie-die" clothes (batiks) for selling, farming (vegetables), livestock (chicken, goats), production (soap making, bread, food processing), enterprising (fishing, bricks making).

Support Needs for TB Vulnerable Groups

Vulnerability is defined as "a set of factors that result in a reduction in well-being (decreased quality of life, increased morbidity/mortality), associated with infections such as TB, malaria and HIV" (Vulnerability and Health Alliance). Groups that are especially vulnerable to TB vary according to the context, and the degree and type of vulnerability results from several overlapping biological, socio-economic and environmental factors. Vulnerable populations may experience a heightened risk of acquiring TB and need support services to access or adhere to care. The challenges of certain vulnerable groups are described in brief below, along with potential social support interventions.

Supporting Patient Caregivers

Another group that can experience the impact of TB disease severely are the family members or other persons who are called on to support and assist a patient through the long and complicated treatment process. Whether the parent of a sick child, or a spouse, sibling or extend family member, these persons may similarly experience considerable challenges related to loss of income and time away from work, stress and anxiety as they view their loved one's illness, fear of infection, stigma or social isolation due to their family member's TB status, and the strain of continually providing care.

Where possible, social support services should be extended to include this group as well. Psycho-social counselling, financial support packages, and direct benefits may be structured to take into account the person responsible for getting a TB patient to their appointment, overseeing their daily care, helping them cope with side effects and encouraging them to stay on their treatment until cure.

Migrant populations include internal migrants (i.e. rural populations moving to urban centers), cross-border migrants (driven by economic, political, or security reasons); floating populations (the homeless, those living in urban slums, etc.); labour migrants (i.e. miners), refugees, and itinerant peoples.

Migrants

Challenges and Needs

Socio-economic

Lack of access to health care services; legal issues (absence of IDs, irregular residence status, work permits, social security documents); poverty, housing, poor working conditions, financial issues, absense of job/instability in employment

Individual/ Psychological

Lack of knowledge of existing available services; illiteracy; lack of familiarity with the local language; poor health-seeking behaviors; psychological distress

Interpersonal/ Social

Cultural beliefs, social isolation, stigma and discrimination

Social Support Interventions

Financial Support Packages

- Providing transportation reimbursement to TB health care facilities for former prisoners;
- Supporting economic independence for former prisoners through vocational trainings, programs, microenterprise activities, job opportunities, etc

Treatment Support Services

- Food provision, especially to undernourished patients;
- Provision with hygienic kits;
- Provision of clothing in case of need
- Temporary shelters for former prisoners on TB treatment in case of need

Psychosocial Support Services

- Counselling, case management;
- Group works, support groups
- Peer education and peer counseling

Linkages with Other Treatment and Social Services

- Establishing linkages between prison health and civilian health facilities, ensuring referal system, consultations of specialists unavailable in prisons from civilian sector
- Ensuring access to TB prevention, diagnosis, treatment and rehabilitation within prison settings
- Access to symptomatic drugs especially for MDR TB patients to address side effects
- Access to integrated health care services to address existing comorbidities, i.e. access to harm reduction program, OST, ART, co-trimoxazole preventive therapy, etc
- Treatment follow up in civilian sector for released patients
- Ensuring access to TB care for former prisoners
- Linkage with legal authoroties in order not to jeopardize access to TB care

Prisoners (Former and Current)

Challenges and Needs

Socio-economic

Lack of access to comprehensive health care services; food insecurity; housing issues, poor living conditions/ overcrowding; employment issues, legal issues

Individual/ Psychological

Existing co-morbidities (HIV, IDU, Hepatitis B/C, STI, mental disorders, malnutrition); illiteracy; lack of motivation

Interpersonal/ Social

Absense/lack of family support; social isolation; stigma and discrimination

Social Support Interventions

Financial Support Packages

- Providing transportation reimbursement to TB health care facilities for former prisoners;
- Supporting economic independence for former prisoners through vocational trainings, programs, microenterprise activities, job opportunities, etc

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- Food provision, especially to undernourished patients;
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- Linkage with legal authoroties in order not to jeopardize access to TB care

People Living with HIV

Challenges and Needs

Socio-economic

Constraints in accessing comprehensive, integrated health care; food insecurity

Individual/ Psychological

Possible other comorbidities (TB/HIV + IDU, viral hepatitis); Psychological distress

Interpersonal/ Social

Absense/lack of family support; stigma and discrimination

Social Support Interventions

Financial Support Packages

- Supporting economic independence through vocational training programs, microcredit loans, microenterprise activites

Treatment Support Services

- Food provision, especially to undernourished patients

Psychosocial Support Services

- Individual counseling on treatment co-ordination, infection control etc;
- Links to HIV patient support networks.

Linkages with Other Treatment and Social Services

- Access to integrated TB/HIV health care services, i.e. availability of ART, co-trimoxazole preventive therapy, etc
- Access to other integrated health care services for other possible comorbidities (TB/HIV+ IDU, viral hepatitis, malnutrition, etc);
- Provision of one-stop-shops to ease accessibility of services.

Injecting Drug Users

Challenges and Needs

Socio-economic

Legal issues; constraints in accessing comprehensive, integrated care; lack of access to harm-reduction programs; employment insecurity; housing issues

Individual/ Psychological

Possible co-morbidities (TB/IDU+ HIV, viral Hepatitis, mental disorders); mental health challenges

Interpersonal/ Social

Absense/lack of family support; stigma and discrimination

Social Support Interventions

Financial Support Packages

- Supporting economic independence through vocational training, microenterprise activities.

Treatment Support Services

- Food packages
- Hygienic kits
- Clothing in case of need.

Psychosocial Support Services

- Individual counseling;
- Group works, support groups, anonymous groups;
- Mental health screening and referrals to services.

Linkages with Other Treatment and Social Services

- Access to integrated health care services: TB treatment along with harm reduction services such as needle exchange program, access to OST, and other possible options of drug dependancy care;
- Access to other TB integrated health care services for other possible comorbidities, i.e. TB/IDU+ HIV, viral hepatitis,etc;
- Access to Naloxone;
- Addressing legal issues: advocacy for decriminalization of IDUs by treatment instead of imprisonment

Children

Challenges and Needs

Socio-economic

Pediatric TB often overlooked by NTPs; food insecurity; Withdrawal from schools and other formal educational institutions due to TB

Individual/ Psychological

Lack of ability to personally advocate for treatment

Interpersonal/ Social

TB spread to children from infected adult family members; requires strong commitment of a caregiver

Social Support Interventions

Financial Support Packages

- Reimbursement of transportations costs.

Treatment Support Services

- Ensuring adequate nutrient intake on the basis of locally available and affordable foods;
- Nutritional supplementation cannot be given directly to an infant under 6 month of age, but can be provided for the lactating mother;
- Nutritional support should include early efforts to continue breastfeeding where possible;
- Addressing other material needs: hygienic kits.

Psychosocial Support Services

- Social support interventions to caregivers;
- Age appropriate patient education and counseling along with caregiver counseling.

Linkages with Other Treatment and Social Services

- Advocacy for recognition of pediatric TB as an important part of NTP with ensuring access to spealized TB care;
- Include the needs of children in research, policy development and clinical practices;
- Introduction of family- centered care approach;
- Advocacy for provision and access to education for children with TB.

Women

Challenges and Needs

Socio-economic

More limited access to health care; financial dependence and insecurity

Individual/ Psychological

Ignorance of TB symptoms; fear of abandonment by husband/family; TB effect on pregnancy; psychological distress

Interpersonal/ Social

Cultural beliefs; stigma and discrimination

Social Support Interventions

Financial Support Packages

- Empowerment of women by supporting economic independence:
  - Microcredit loans;
  - Vocational progrms;
  - Microenterprise activities;
  - Transportation reimbursements to health care facilities.

Treatment Support Services

- Food packages;
- Hygienic kits;
- Clothing in case of need;
- Providing temporary shelters, i.e. in rehabilitation centers for women in case of need;

Psychosocial Support Services

- Individual counseling;
- Self-help, support groups for women.

Linkages with Other Treatment and Social Services

- Basic access to health care with tolerance to cultural specificities, availability of women health care providers;
- Adressing gender based issues in certain societies where women do not make the decision to seek healthcare no matter how ill they are;
- Access to integrated health care, i.e. TB+pregnancy, etc;
- Community-based insurance schemes.

Ethic Minorities

Challenges and Needs

Socio-economic

Limited access to health care; employment insecurity; financial insecurity; legal and bureacratic barriers

Individual/ Psychological

Language and cultural barriers

Interpersonal/ Social

Culutral barriers; Marginal social status.

Social Support Interventions

Financial Support Packages

- Supporting economic independence through vocational training, microenterprise activities, microcredit loans

Treatment Support Services

- Food packages;
- Hygienic kits;
- Clothing in case of need

Psychosocial Support Services

- Individual counseling;
- Self-help, support groups administered in local languages.

Linkages with Other Treatment and Social Services

- Advocacy for UHC of TB care along with general population without depriving of any rights of ethnic minoroties;
- Possibilities for community health coverage schemes to cover along non medical expenses;
- Linkages to support networks and organizations working ethnic minorities;
- Translation/ adaptation of messages and information in local languages.

Organizing Social Support Services

Direct Service Delivery vs. Developing a Coordinated Service Network

Supporting TB patients can be done directly by the TB services providers, either through the National TB Program, clinic staff and DOTS providers, or through NGOs and organizations targeting TB patients (i.e. community treatment supporters or DOTS workers). Several countries have taken steps to incorporate support programs, often based around incentives for treatment intake and adherence. Many of these programs incorporate economic support as performance- based financial or material incentives for patients to complete their TB treatment. For this discussion, incentive is defined as "all financial or material rewards that patients and/ or providers receive, conditional on their explicitly measured performance or behavior" (definition by Alexandra Beith and her colleagues).

Whether provided through direct financial incentives or incentives involving material support, one danger of offering such incentives to encourage patients to be tested or to continue treatment is that some beneficiaries might misuse or react by engaging in practices that allow them to continue to qualify. These may be unintended effects of such incentives and proper establishing of systematized monitoring system to identify and correct them are essential parts of program design and implementation.

Another concern which may arise in relation to incentive schemes is one of sustainability. When services are provided through donor support or administered by NGOs or technical assistance partners, maintenance in the long term and the potential to transfer responsibilities or the management and financing of the incentive programs to the local authorities or a local organization needs to be addressed.

EXAMPLE

Linking with the Passport Issuing Authorities to Renew Lost IDs for TB Patients in the Prison System

Assistance with obtaining a national identity card for prisoners on TB treatment before they will be released in a good example of such network support., for example, in St. Petersburg, Russia as a part of comprehensive needs assessment approach inmates were asked on what would them motivate to finish their treatment after release. The most highly valued incentive was obtaining of documentation, ID cards for further opportunities to work, for housing, accessing public services. Lack of ID cards has a greater likelihood of police harassment and re-incarceration.

However, in most cases it is unlikely that a TB program or organization alone will be able to provide the comprehensive range of social support services discussed above. Rather, programs and providers may focus on developing coordinating mechanisms and linkages with other services, aimed at fostering a network of services including the TB facility as well as sources of support outside the TB program. There will be many players in TB control or a particular setting including governmental, non- governmental organizations, international partners, community-based initiatives, and others. No single entity will be able to address all different types of patient's social needs, but each organization should tapped to refer, link and give information to assist those needs.

Considerations for Program Planning

Partnerships and Types of Service Organizations

For efficient and effective social support programs, it is essential to develop a legal basis for provision of social assistance to beneficiaries and to create an institutional framework with linkages between TB facilities and other partners who can assist in support of TB patients.

Establishment of a partnership network is a key activity for collaborating with other stakeholders involved in TB programs. Moreover, these networks build a basis for referral relationships between organizations to respond in a comprehensive way for patient's social needs.

Some of the essential blueprints for productive partnerships are:

- Define and formalize the relationships between organizations, referral procedures, and harmonization of common activities between service providers so stakeholders agree on procedures;
- Identify an organization to take a leading role as a coordinating organization for a particular activity;
- Identify existing gaps in services and take steps to bridge them;
- Seek out new partners, but do not underestimate existing ones;
- Clearly identify the scope of work your partnership will undertake.

Figure 4. Partnership for Social Support

Figure 5. TB Social Support Partnership Models

Scopes for partnerships may include:

- Advocacy for inclusion indirect costs such as sick leave allowance, including temporary disability allowances especially for MDR TB patients;
- Improvement of employment protection to enable patients to be able to return to previous positions once they are cured and clinically fit to perform their assignments as well as advocating for regulations and policies that mandate employers pay employees (a portion of) their designated salary while they are on sick leave;
- Engagement of social workers and social welfare systems to assist migrants, ethnic minorities, former prisoners, vulnerable children, and others to navigate legal and organizational obstacles to receiving care.

Steps for Getting Started

Developing an effective social support network for TB patients requires considerable effort and resources, but is vital to making any long term impact against the disease. Some of the steps involved are captured in Figure 6.

A key starting point is to map the needs and vulnerabilities of TB patients in a given setting. This mapping activity should include: 1) identifying the demographic profile of TB patients; and 2) identifying patient social support needs.

1. Identify the demographic profile of TB patients

This includes collecting information on the key characteristics of the TB patients in a given areas, and mapping the frequency of TB disease relative to certain demographic profiles to identify persons with high risk of TB. Key demographic information may include:

a. Age

b. Sex

c. Housing status

d. Employment

e. Family size

f. Primary language

g. Socio-economic status

h. Frequency of other key co-morbidities

i. TB status- DS TB, DR TB, re-treatment

2. Identify patient support needs

Recognizing that not all TB patients will have the same set of vulnerabilities and will require the same package of services, a next step is to identify the key challenges TB patients face relative to accessing and adhering to treatment. This may be done through patient, provider and care giver interviews or focus group discussions and/or targeted assessments, death audits, default surveys or similar exercises geared at identifying the specific barriers patients experience in obtaining diagnosis or maintaining treatment.

A secondary analysis involves identifying the services opportunities and partnership possibilities in your area. A stakeholder analysis of the key service organizations, their scope, reach, and activities can lay the foundation for developing a constructive partnership, with mutually defined responsibilities.

Finally, the need for social support services for TB patients requires a great deal more advocacy and attention at the highest level, to ideally lead to an integrated policy framework to ensure that all TB patients are able to access the comprehensive range of assistance they need. Opportunities to participate in this advocacy and to promote dialogue and sharing of lessons on how to effectively organize support networks should be sought whenever possible.

Figure 6. Developing a Social Support Network for TB Patients

1. Need assessment

- Existing laws, legislation on Social Protection for TB patients
- Existing Social Support (SS) Services
- Identifying gaps in existing SS services
- Identifying vulnerable groups

2. Stakeholder analysis

- Organization description
- Potential role
- Level of commitment
- Available resources
- Constraints

4. Partenership advocacy

- Legislation of Social Protection schemes
- Broad involvement of national bodies for sustainability of SS services

3. Developing collaborative partnerships

- Statement of common goals & activities
- Adressing existing gaps
- Setting up referral procedures
- Maintenance of relationships & follow up

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