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Psychosocial support groups for patients with multidrug-resistant tuberculosis: Five years of experience

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Abstract
This detailed case history traces the first 5 years of a psychosocial support group intervention aimed to improve adherence to individualized drug regimens for multidrug-resistant tuberculosis (MDR-TB) in Peru. A total of eight groups were established in metropolitan Lima and two provinces of Peru led by teams of psychiatrists and nurses. The intervention consisted of bi-monthly support groups, recreational excursions, symbolic celebrations, and periodic family workshops. Notably, of the 285 patients who participated in this intervention, only 3.5% defaulted from treatment. Details include the description of services, patient data, major psychosocial difficulties faced by this population, key challenges, and implications. Psychosocial support is a crucial component of treatment for MDR-TB in order to ensure completion of complicated treatment regimens and enable psychosocial rehabilitation after treatment.

Keywords: Psychosocial support, support group, multidrug-resistant tuberculosis, adherence, stigma, Peru

Introduction
Despite the existence of effective and inexpensive chemotherapy, tuberculosis (TB) claims the lives of roughly 1.7 million people per year (World Health Organization 2006). One of the challenges to controlling the TB epidemic has been the recent emergence of antibiotic drug-resistance. Multidrug-resistant tuberculosis (MDR-TB), defined as resistance to at least two of the most powerful first-line drugs, isoniazid and rifampin, has been found in every region of the
world (World Health Organization 2004). Anti-tuberculosis drug resistance develops when the medications are taken inconsistently, either due to health system failures or poor treatment adherence.

Treatment of MDR-TB is possible, but may cost as much as 100 times more than drug-sensitive TB (Gupta et al. 2001, World Health Organization 2002), which is an obvious problem in resource-poor settings. However, the failure to treat these patients will prove to be significantly more costly in the future (Farmer et al. 1998). Without proper treatment, the problem of MDR-TB will not disappear; it is estimated that each patient who does not receive effective therapy will, every year, infect 10–15 people (World Health Organization 2006), in this case with highly drug-resistant strains. Therefore, once treatment becomes available, treatment adherence is central to the success of programmes: to cure disease, curb transmission, and to prevent the emergence of increased drug resistance.

Due to the difficult treatment required for MDR-TB, ensuring adherence can be a significant challenge. A recent review article, by Mukherjee and colleagues (2004), describes 13 MDR-TB treatment cohort analyses, from Denmark, Netherlands, USA (4), Canada, Turkey, Peru (2), Hong Kong, and South Korea (2), in which default rates ranged from 0–39%, with an average of 12.6% among the studies. Two, more recent, cohort studies in Argentina and South Korea revealed default rates of 19.9% and 28.9%, respectively (Palmero et al. 2004, Park et al. 2004). These studies highlight the need to find effective strategies to promote treatment adherence so as to ensure positive outcomes and prevent further transmission of MDR-TB.

Treatment of MDR-TB requires complex regimens, including powerful combinations of second and third-line anti-TB drugs which are both weaker and more toxic than the first-line drugs. The result is that treatment for MDR-TB is long (generally 2 years) and painful, involving daily injections for a minimum of 6 months, as well as many unpleasant side effects. In one cohort study of 60 patients being treated for MDR-TB, the most common adverse effects included gastritis (100%), dermatological effects (43%), and peripheral neuropathy (16.7%) (Furin et al. 2001). While many of the side effects are temporary, others, such as hearing loss, may be irreversible. Furthermore, psychiatric complications have also been associated with some of the medications. When the same cohort was expanded to include 75 patients, the incidence of depression, anxiety, and psychosis during MDR-TB treatment was 13.3%, 12.0%, and 12.0%, respectively (Vega et al. 2004). Aggressive and effective management of these side effects was necessary in order for patients to tolerate treatment and remain adherent.

Beyond side effects, several psychosocial factors also challenge the ability of patients to adhere to treatment. The majority of patients live in poverty and the disease puts a further strain on their families. Due to symptoms of the disease and medication side effects, many patients are unable to work or fulfil other social roles during treatment. As a result of giving up or postponing important activities or goals, including work and education, many patients feel frustrated and
‘useless’. Furthermore, the social stigma associated with MDR-TB can have negative consequences on patients and their families, including social rejection and isolation, internalized shame, financial instability, discrimination, and other repercussions (Sweetland et al. 2002). Finally, due to previous treatment failures, many patients struggle to maintain hope after being told by health professionals that no treatment was left for them. Not surprisingly, more than half (52.2%) of the initial cohort of patients in treatment for MDR-TB in Lima was diagnosed with a depressive syndrome at baseline (Vega et al. 2004). Due to the multiple, complex difficulties faced by patients, the development of successful strategies to support patients is essential to ensure treatment adherence and, consequently, to effectively control the MDR-TB epidemic.

Interestingly, the origins of the ‘group psychotherapy’ method are rooted in the work of Joseph Pratt, a Boston internist, who, in 1905, piloted group work with TB patients who could not afford to enter sanatorium care (Pratt 1907). Subsequently, group psychotherapy was used with TB patients in several settings (Adler 1953, Kienast et al. 1965, Hunsicker et al. 1967). More recently, group therapy has been used in a variety of settings to improve the quality of life and survival among other medically ill patients (Spiegel et al. 1989, Spira 1997, Goodkin et al. 2001). Group therapy has also been demonstrated to reduce depression and the disability associated with it (Bolton et al. 2003). This paper outlines our observations and insights from 5 years of using a psychosocial support group intervention for patients with MDR-TB in Peru.

Methods

Data collection

A variety of qualitative methods were used to gather the data presented in this paper. Qualitative methods have a long history of use in the health sciences, and provide valid data on research questions about which little is known (Yach 1992). Specific methods included participant observation, informal focus groups, and extensive documentation including session summaries and transcripts. For 3 years of the 5-year period of the study, one of the authors (A.S.) participated in all possible psychosocial support group sessions as a participant observer. Detailed field notes recorded the topics that surfaced in the groups, with particular attention given to the strategies used by different group facilitators to address these themes, peer interaction, as well as the dynamics between the facilitators and the participants. In addition, salient quotes were recorded. The second source of data came from informal focus groups that were held in July 2001, which represented the juncture at which the decision was made to extend the pilot support group from northern Lima to other areas. Four interest groups were identified and asked to participate, which included: current patients who had attended fewer than ten sessions of the psychosocial support groups; cured patients who had attended ten sessions or more; family members of patients who attended the sessions; and community health workers who worked with patients...
that attended the sessions. Participants were asked to comment on the content of the sessions, the impact of the psychosocial support groups on patients’ lives, the ways in which the groups influenced patients’ attitudes about their disease and treatment, and to provide suggestions for future groups. The final source of data came from documentation of the sessions. After every session, the group facilitators wrote general summaries which recorded attendance, main themes discussed, and logistical challenges. In addition, transcripts were made for a subset of approximately 20% of all sessions (42 sessions representing six of the eight different psychosocial support groups discussed in this paper).

An Access TM database was created to catalogue sessions, attendance, topics discussed, and logistical concerns. These topics were then categorized and a list of common themes generated. The most common themes (determined by frequency) were then analysed by comparing the data available from the group summaries, field notes from the participant observer, focus group notes, as well as the available session transcripts. The field notes and session transcripts were then used to extract the quotes reported in this paper.

**Intervention**

Beginning in March 1999, a psychosocial support group intervention was organized for patients with MDR-TB in northern Lima, Peru, an early report of which is detailed elsewhere (Sweetland et al. 2002). The psychosocial support group intervention consisted of four components, including support groups, recreational excursions, symbolic celebrations, and family workshops. (A guide has been developed in Spanish by the authors to share insights, methods, and strategies, and is available upon request.) Many patients also gathered informally between sessions, which was seen as an indirect benefit of the intervention.

There were three primary inclusion criteria for participants. The first criterion was that the patient was currently receiving individualized treatment for MDR-TB through a partnership programme between the Peruvian Ministry of Health and Socios En Salud/Partners In Health (SES/PIH), a community-based non-governmental organization. All patients received directly observed treatment (DOTS-Plus) on an outpatient basis through local hospitals, health clinics, and daily home visits by community health workers, using regimens that were based on individual drug-sensitivity tests. A second criterion was that a participant had a minimum of two negative culture results, and therefore posed a low likelihood of infectious risk. Finally, all participants had been identified, by a nurse and/or community health worker, for exhibiting signs of emotional difficulties (feeling sad, depressed, or withdrawn), risk of suicide (ideation or attempt), risk of treatment default (multiple missed doses or expression of desire to default from treatment), and/or weak social support.

Patients with positive culture results, and patients exhibiting severe psychiatric symptoms, were excluded from the groups, and individual psychiatric attention was provided instead. Infectious patients were temporarily excluded to prevent the possibility of TB reinfection, as this risk has been documented in the literature
Nardell et al. 1986). Patients with severe personality disorders, or patients experiencing acute psychosis as assessed by a psychiatrist, were excluded due to the risk they posed for disrupting group dynamics. Participation in the groups was ostensibly voluntary, though sometimes the health workers would attempt to persuade patients the team felt would benefit from the intervention but who were reluctant to join. All persuasion techniques were non-coercive and included such strategies as offering encouragement, subsidizing transportation costs, and providing transportation and/or accompaniment.

The support group sessions convened weekly, and later bi-monthly, with an average of 8–12 patients in each session. The team of health workers that participated in the sessions were comprised of nurses, social workers, community health workers, and psychiatrists. In addition to the patients, one or two cured patients were invited to each session to offer testimonies and provide support to those individuals still in treatment. Generally, a psychiatrist and nurse team co-facilitated the sessions (specific facilitation methods are described later), and the health workers intervened when necessary to encourage group participation. Group membership fluctuated over time as some patients finished treatment and/or voluntarily withdrew and newer patients were integrated.

Several times a year, daytime recreational excursions to the outskirts of the city were organized for patients, cured patients, and the health working team. Symbolic celebrations were also held for patients, including the recognition of birthdays, treatment completion, international TB day, Mother's and Father's day, Christmas, and other significant holidays. On several occasions, workshops were organized for patients and their families. During these special sessions, family members were invited to participate, and were encouraged to interact with other patients with the ultimate goal of increasing their awareness and understanding of the disease and treatment. Monthly interdisciplinary team meetings were also organized among co-facilitators from different support groups to share experiences and insights, discuss salient cases, troubleshoot logistical challenges, plan for future activities, as well as ensure continuity among the various support groups.

In late 2000, a formal collaboration was established among the Peruvian Ministry of Health, the World Health Organization, the US Centers for Disease Control and Prevention, and SES/PIH, to expand MDR-TB treatment services from northern Lima nationwide. As services were extended, five more psycho-social support groups were introduced, in addition to the original group established in northern Lima, throughout metropolitan Lima, between May 2002 and March 2004: in northern Lima (at SES/PIH, Hospital Sergio Bernales, and Hospital Materno Infantil San José), southern Lima (Hospital Maria Auxiliar), Lima Ciudad, and Callao. Additionally, two groups were established outside of Lima, in the provinces of Ica (Hospital Regional de Ica) and Trujillo (Hospital Regional de Trujillo).
Results

Attendance data is available for 168 of the 197 group therapy sessions (85.3%) held between March 1999 and March 2004, the rest of which were, unfortunately, unrecorded or misplaced. According to the available data, a total of 285 patients participated in these eight psychosocial support groups at least once, and for an average of six sessions. Participants had documented resistance to an average of six drugs (range 1–13) and all were receiving individualized drug regimens based on drug sensitivity testing. Most of these patients completed (unsuccessfully) multiple previous treatment regimens prior to initiating individualized therapy (an average of three previous treatments, range 0–9), and had been living with MDR-TB for a median of 4.5 years (range 7.2 months to 24.7 years) upon attending the first session of group therapy. The gender balance was roughly equal: 52.3% of the patients were male. While their ages ranged from 11 to 67, most members were young; the median age upon joining the support group was 27. Half of the patients (52.6%) had at least one close family member with a history of TB (range 1–8 family members), and about one quarter (24.2%) had at least one deceased family member due to TB (range 1–4 family members). Forty percent had completed high school. Notably, of the 285 patients, the majority (93.7%) received cycloserine as part of their anti-tuberculosis regimen, the drug most strongly associated with psychiatric complications (Vega et al. 2004).

Participation varied widely. Patients participated in an average of six sessions, however a large percentage of patients (66.3%) participated between one and five times only, and a minority of patients (10.6%) participated in more than 15 sessions each. It should be noted, however, that participation rates do not take into account the abundance of undocumented activities that were spawned by the group intervention (mutual home visits, weekend socialization, and significant friendships among group members) all of which could be seen as indirect consequences of this intervention and may have contributed to overall treatment adherence. Also, 11% (32 patients) participated for the first time during the final 6-month period of study.

As of March 2004, 171 patients had been cured (60.0%), three relapsed (1.1%), nine died (3.2%), ten defaulted (3.5%), and 90 remained in treatment (31.6%). Of the ten participants who defaulted from treatment, seven had participated in only one session, the three remaining participated in two, three, and five sessions each. Among those who participated in only one session, the reasons for default were: moved away (2), religious beliefs (1), side effects (2), work (1), and belief in being cured (1). Of the remaining three patients, one was a minor who was removed from treatment by a parent, one abandoned for religious reasons, and one defaulted because his family opposed treatment and he believed he was cured.
Therapeutic strategies

Several general strategies were used by facilitators in the support groups. Most facilitators used moderately directive techniques to elicit patient testimonies and facilitate group discussions. Sessions generally began with an open invitation by the facilitator to participants to bring up any topic of concern or interest. In the event that no participant offered a spontaneous contribution, facilitators would often ask questions to specific patients in order to initiate dialogue. Once a topic with therapeutic value surfaced, the facilitators would then rely on a variety of techniques to facilitate the group dynamics. One strategy included focusing on the specific situation of a patient experiencing difficulties. The facilitator would ask the individual probing questions, reflect and summarize key issues illustrated in the testimony, and then invite other group members to comment or offer support to that individual. Another strategy used by facilitators included taking an issue presented by an individual patient and generalizing to a broader group of patients. For instance, if the patient expressed difficulties tolerating side effects, the facilitator would ask the group if anyone else had experienced similar difficulties and how they overcame them. This latter strategy appeared to serve dual purposes of providing support to the individual in need as well as fostering a community of shared experiences among patients. When topics surfaced that involved misconceptions, such as how MDR-TB is transmitted, the facilitators intervened to provide education and correct false ideas.

Thematic content of sessions

Several common themes emerged in the support groups, the first of which was related to social cohesion. The climate of camaraderie that developed in the groups led some patients to refer to each group as a ‘family’. The common experience of struggling with MDR-TB treatment appeared to serve as the bond for this social network, bringing together an otherwise heterogeneous group of individuals into a cohesive unit. The trust cultivated in the groups enabled patients to confide their problems, the scope of which often spanned well beyond those related to the disease or treatment, including personal problems and those related to struggles for survival while battling conditions of poverty.

One of the most significant therapeutic challenges in the groups was combating the profound consequences of stigma on the social and emotional lives of patients. Most patients held deeply engrained negative views about their disease and, consequently, about themselves, as manifested in feelings of guilt, shame, and self-blame. This often made it difficult for patients to accept their disease and its associated treatment. Most patients had experienced, to varying degrees, social rejection and discrimination from family members, friends, neighbours, and/or health providers. Some reacted to these experiences by isolating themselves and most made a concerted effort to keep their disease a secret. As a result, for many patients the support groups appeared to be one of the only places in which patients could speak freely about their experiences and feelings, and receive
empathetic support from others. The following testimony by a patient who had completed treatment illustrates this phenomenon:

Thanks to the therapy group, I met a group of people to whom I could say, ‘I have this disease!’ I am no longer locked up in my room, trapped between four walls. Sometimes I would even talk to the walls. I would ask God, ‘Why do you punish me, so?’ But now I realize that it wasn’t a punishment because I met a group of real friends, ones that I could truly consider friends and tell them what I’m feeling. And now I’m cured.

Considering treatment default or suicide were other topics that surfaced frequently. Importantly, because the consequence of treatment default is generally fatal, these topics were closely related. While these issues were addressed directly by the facilitators, in large part, support came from the other group members. Because of the extraordinary difficulties faced by the patients, most shared these sentiments, which fuelled their motivation to assist other patients in crisis. Their common experiences made it possible for patients to identify rapidly with one another on an intimate level, and to offer both emotional and pragmatic support by sharing ‘tricks’ and strategies to improve tolerance of side effects and coping with depression and hopelessness. Patients who had overcome these moments of severe depression convinced newer patients that these feelings marked a stage in the course of their illness, and inspired confidence that the feelings would pass.

All of us go through that (suicidal ideation); that’s normal. The beginning of treatment is so hard, but it gets easier. I thought about killing myself many times. The side effects were so bad; I was so depressed. Treatment seemed like an eternity. But little by little, things got better. We have to be strong. We can’t give up. The most important thing to know is that you’re not alone. We’re all in this together.

Sharing complaints about medication side effects was another common theme. While some patients claimed that listening to others’ physical complaints diminished their ability to ‘forget’ or tolerate their own side effects, it was clear that mutual acknowledgement of physical suffering offered patients the opportunity to commiserate with one another, and enhanced solidarity among members. One of the more difficult side effects to tolerate was nervios or irritability (likely due to one medication, cycloserine) that had negative effects on patients’ personal relationships. Frequent nausea and vomiting were also common, and patients commiserated over this with one another, and shared concrete strategies to minimize this reaction. For example, one patient told the group:

I used to throw up every day. As soon as I would hear the health worker’s knock on the door, I would begin to feel nauseated. I would take the medicines, and then throw up immediately. The worst was that then I would have to take them again, and again, until I could get them to stay down. I found that when I would take them on an empty stomach, it was worse. Now I take them with fruit, or yoghurt, and it helps. It takes the taste out of my mouth and I’m able to resist (vomiting). Now I rarely throw up. I’m able to keep them down, but always on a full stomach.

Another very difficult side effect was the darkening of the pigmentation in the skin that was caused by one medication, clofazamine. Negative attitudes towards darker skin colour in Peruvian culture made this particular side-effect difficult to
manage, especially when compounded by the marginalization these patients already experienced due to their disease. Patients reported constantly needing to deflect comments and questions about their skin colour to friends and neighbours, while attempting to keep their disease a secret, often being reduced to lies. As one patient expressed:

I’ve had to learn to be a liar. When people ask why my skin is so dark, I say I’ve gone to the beach, or into the mountains. I mean, what can I do? I have to come up with whatever lie I can besides the truth, anything but the truth, because if they found out the truth, they would discriminate against me. Who wants to be marginalized? One has to lie.

The support groups helped patients to accept their pigmented skin, emphasizing that their health was most important, and that they would have to tolerate this side effect in order to be cured of their disease. As one patient summarized, ‘I just think of it as “either I’m black or I’m dead” and I want to live’.

Another common frustration among patients was related to the restrictions imposed by their disease and/or treatment. Due to MDR-TB, many patients experienced physical ailments related to their disease, such as shortness of breath, fatigue, or wasting, in addition to various physical side effects caused by the medications, such as headaches, gastritis, or peripheral neuropathy. These physical ailments prevented some patients from fulfilling important occupational or social roles. Often younger patients had to overcome the frustration of thwarted plans to study and develop personally and/or professionally and put their lives on hold while they struggled to overcome the disease. Former wage earners strained to overcome feelings of ‘uselessness’ and being ‘a burden’ on their already struggling families as a result of their inability to work. Many patients were also frustrated by social limitations; some lacked energy to adequately care for their children, and others experienced difficult strains on their intimate relationships. Cured patients helped to illustrate that these limitations were often temporary. For example, one patient whose occupational specialty was to make brooms recalled:

When I was healthy, I used to be able to make 200–300 brooms a day. When I was in treatment, I only managed to make 3–4 a day. I used to get really tired. Now that I’m cured, I can make more and more. First I made 20, then 30... now I can make 100! Little by little you return to normal. It’s still not as much as before, but I’m improving.

Finally, due to years of illness, many patients had grave doubts as to whether or not treatment would be effective. Previous treatment failures had taught them to be skeptical, and this seed of doubt often persisted throughout the 2-year treatment. Patients shared painful testimonies of being told by health professionals, often harshly, that no treatment was left for them due to their drug resistant disease. For instance, one patient shared, ‘They told me, “don’t waste any more of your family’s money. You’d be better off just buying yourself a coffin”’. Understandably, conflicting messages from health staff fuelled a sense of uncertainty and mistrust, as patients did not know whom or what to believe. This also contributed, in part, to a widespread myth that this ‘alternative’ (individualized) treatment was just an ‘experiment’, a suspicion that was seemingly
confirmed by the profusion of side-effects induced by treatment. As another patient shared:

My family didn’t want me to take this treatment because, they said, ‘they just want you to be a guinea pig in their experiment!’ But I decided to take it anyway because there were no other options for me. It was my only chance.

It was in addressing these particular issues that the participation of cured patients was indispensable; they validated patients’ concerns, while serving as powerful models and inspiring hope in patients still in treatment.

**Recreation, symbolic celebrations, and family workshops**

The periodic excursions were opportunities for informal socialization and recreation. On these occasions (which generally included various activities such as soccer, volleyball, dancing, and games such as relay races) patients expressed the relief and pleasure of getting away for a day, out of their homes and their routines centred around pill-taking. Many said that these excursions felt like ‘mini vacations’ from their difficult regimens and gave them hope that life after treatment might resemble the ‘normality’ that they glimpsed on these occasions.

The symbolic celebrations were often emotive events regularly including speeches, testimonies imbued with feelings of solidarity and mutual support, and reflections about their disease, treatment, and life after treatment. During the family workshops, patients and family members alike were encouraged to look beyond their specific familial experience to the general ways in which MDR-TB impacts families in a way that appeared to increase mutual understanding and support.

**Key challenges**

Due to the setting of poverty in which these groups were hosted, there were several challenges in establishing and maintaining the support groups. Some ongoing logistical difficulties included finding adequate and low-cost meeting places, ensuring attendance, tardiness and delays (in large part due to Peruvian custom), finding willing facilitators, securing the resources to finance the sessions and excursions, and subsidising transportation costs in necessary cases. Finally, lack of prior experience, addressing issues associated with social stigma, and creating a replicable model, were all ongoing challenges.

Several factors impacted attendance rates, such as conflicting caregiving duties, sporadic work opportunities, and physical difficulties associated with the disease or treatment. Other patients insisted that they did not wish to participate because, they would say, ‘listening to others’ problems makes me more depressed’ or ‘hearing others’ physical complaints makes me feel worse’. For these patients, a concerted effort was made to encourage them to attend several sessions before making a final judgment. Often, after participating in several sessions, the opinion of these patients changed, and they became regular members.
Another significant challenge was related to finding qualified and willing group facilitators, a problem that merits significant attention. Despite the fact that MDR-TB is a treatable disease, misconceptions and fear surrounding the disease still abound, even within the health care system. As a result, despite the fact that only non-contagious patients participated in the groups, it was often difficult to find mental health professionals to lead the groups in the local hospitals and health centres. Some of the more candid professionals admitted, simply, being ‘afraid’ to work with MDR-TB patients. Since guilt, shame, and the fear of rejection are primary concerns of MDR-TB patients, we decided that it would be imprudent to solicit the services of mental health professionals with these biases because, rather than helping patients to overcome these difficulties, their prejudices would likely be perceived by the members and would contribute to feelings of alienation. In the end, six psychiatrists and seven nurses were identified (some facilitated more than one group); the psychiatrists all had previous training in group psychotherapy and the nurses learned through modelling and helped to co-facilitate the intervention. Periodic meetings among this group helped to facilitate the exchange of insights and experiences, as well as ensure more continuity among the groups.

The lack of prior experience with similar interventions for patients with MDR-TB was another challenge we experienced in the implementation of psychosocial support groups. While many similarities can be found between the psychosocial needs of individuals affected by other stigmatized infectious diseases associated with poverty, such as HIV/AIDS, there are several characteristics of MDR-TB that have a psychosocial impact on patients and required innovation. Principal among these are the airborne infectiousness and consequent multiple infections within households, catastrophic loss in some families (due to the previous lack of access to treatment), the prolonged latency period, and novel side effects (dermatological and psychiatric) which posed unique challenges.

Finally, in light of the complexity of emotional and social problems faced by patients, we struggled to reconcile how this model could be replicated in community settings that host few mental health professionals, such as in the rural provinces of Peru or in other international settings. In fact, the difficulties we experienced in finding facilitators, even in Lima, where there are numerous professionals, illustrate the potency of the stigma and fear associated with MDR-TB and the significant challenge this poses. We found that despite having little or no formal training in mental health, the nurses who served as co-therapists with the psychiatrists were able to learn by example and develop therapeutic strategies to facilitate effective interventions in the groups. If psychiatrists could not attend sessions, the nurses filled the therapeutic role and ran the groups. In fact, in one group, when one of the psychiatrists had to withdraw from a group for personal motives, a nurse and social worker co-facilitated the sessions, without the aide of a group psychotherapy specialist. While this task was difficult for the nurses, they showed extraordinary capability and, by their example, demonstrated the
feasibility of replicating this intervention in other settings that do not have access to formally trained mental health professionals.

Conclusions

Treatment adherence is central to the control of the TB epidemic: to achieve cure, limit the spread of disease, and prevent the development of further drug resistance. However, the constellation of difficulties faced by patients requires innovation on the part of care providers, in order to find ways to support patients to overcome these challenges. Numerous studies examining the factors that contribute to non-adherence among patients with drug-sensitive TB implicate side effects (Jaiswal et al. 2003, Wares et al. 2003) and psychosocial factors (Barnhoorn and Adriaanse 1992, Sumartojo 1993, Demissie and Kebede 1994, Johansson et al. 1999, Long et al. 2001). Considering that both side effects and psychosocial difficulties are significantly more complex for patients with MDR-TB than for drug-sensitive TB, it is clear that more research is needed to examine the impact of these factors and to explore innovative strategies that may help patients to adhere to difficult medication regimens.

A recent study in Ethiopia found that the formation of ‘TB clubs’ (a psychosocial group intervention similar to the one described in this paper) increased both treatment adherence and cure rates, in addition to lowering stigma associated with the disease (Demissie et al. 2003). Another study in India found that individual psychotherapy, utilizing principals of motivational interviewing among drug-sensitive TB patients with no mental illness, contributed to significantly higher rates of treatment adherence (Janmeja et al. 2005). In our experience, psychosocial support groups have proved useful in helping patients manage some of the difficulties associated with treatment. The perceived efficacy and low-cost of the intervention were important considerations. However, it is our distinct impression that the psychosocial support groups have had a broader impact than just adherence, including the generation of important social networks and improvement of quality of life. The support group method also proved to be effective in combating the negative social impact of the disease. Due to a combination of social stigma and fears of contagion, most patients were socially isolated and many had withdrawn from customary roles and functions within their families. In this way, the support groups have often played an important role in patients’ social rehabilitation. The social networks established among participants seemed to fill much of the void created by relationships lost in the wake of their disease, and many of the friendships formed among members have lasted long after treatment was completed. Furthermore, most participants who have completed treatment have now successfully reintegrated into their social and community lives; they have returned to work, recommenced their studies, and resumed former family roles and responsibilities.

Finally, the success of the psychosocial support groups has important implications for the responses to other diseases with biosocial roots, such as HIV/AIDS. There are many parallels between the MDR-TB and HIV/AIDS
epidemics, in particular the relationship with poverty, stigma, inequality, and limited access to appropriate care by those most in need of it. In fact, the two diseases together literally form a deadly combination. Once treatment becomes broadly available, in both cases strict adherence to drug regimens will be crucial to prevent the emergence of drug-resistance. However, even after the lack of access to treatment is remedied, the psychosocial impact of both these diseases merits significant attention. In our experience, psychosocial support groups have been a very useful means to respond to these challenges and improve quality of life, and we feel that other such methods deserve significant attention and exploration in order to facilitate more integrated and improved responses to the control of these epidemics worldwide.

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