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# A Review of 57 Zone: A social media network for TB consultation and communication in Kunming, China

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A Review of *57 Zone*: A social media network for TB consultation and communication in Kunming, China

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## Abstract

Yunnan, a predominantly agricultural province in southwest China, is a province with a high rate of both tuberculosis (TB) and multi-drug resistant tuberculosis (MDR TB), with nearly 25,000 cases of pulmonary TB reported each year. Former TB/MDR TB patients in Yunnan, with the support of Family Health International 360 NGO (FHI) are trying to combat this problem. They have created a social media network for TB consultation and communication, 57 Zone, where TB patients can talk about their medication, adverse drug effects, and nutrition and psychosocial concerns. The goal of this study was to look at what aspects of the program help patients adhere to their TB treatment, as well as what participants feel are the greatest benefits of the program, and what they feel could be improved or changed. Then 57 Zone was compared to other TB support programs around the world in order to provide further suggestions for improvement. To collect information, four interviews were conducted with participants who all hold different roles in the program, including an employee of FHI, a nurse, and two peer-counselors. Participant observations at 57 Zone group meetings as well as informal conversations with online participants were also used to collect information. Results showed that the aspects of 57 Zone with the greatest benefit to participants are the in-person counseling opportunities, as well as the accessibility of the online QQ groups for peer-support. Suggested improvements or additions included better management of the QQ group, even more counseling opportunities, more counselors in hospitals, more financial aid opportunities, and expanding the program to other provinces. Overall this study has found that while there are some suggestions for improvements, this program has shown great success and has contributed to the lower rates of TB in Yunnan by helping patients truly understand their disease, as well as by making them more confident to finish their treatment. With more research and continued improvement, this program could become a model for future patient-support programs around the world.

Keywords: Tuberculosis, Public Health

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## Introduction

China has the second largest tuberculosis epidemic in the world. It is estimated that over 1 million people get TB every single year in China, which is more than any country except India. Not only is TB a problem in China, but also 63,000 out of 1 million Chinese people with TB have multi-drug resistant TB (MDR TB)<sup>1</sup>. This means China is contributing one third of the entire world's MDR TB epidemic. There are many reasons for these high rates of TB and MDR TB in China, and each province tells a much different story. Yunnan, a predominantly agricultural province in southwest China is one of the provinces with a high rate of both TB and MDR TB, with nearly 25,000 cases of pulmonary TB reported each year<sup>2</sup>. There are many factors that contribute to the spread of TB and MDR TB in Yunnan, including the difficulty of diagnosing somebody with TB (a common problem as each person presents a unique case), as well as financial and social barriers to treatment<sup>3</sup>. Overall, Yunnan is a diverse province in both wealth and landscapes, and so there are many poor rural areas that only have access to village level health providers but are quite a distance from larger health facilities. In fact, about 74% of Yunnan's 46 million population are reported to live in rural areas<sup>4</sup>. Yunnan is also one of China's most ethnically diverse provinces with 25 ethnic groups, many of whom live in the poorest parts of Yunnan, which along with language barriers creates many difficulties for TB patients. All of these difficulties can result in patients stopping taking their TB medication, which is a huge risk factor for acquiring MDR TB.

The goal of this study was to look at what aspects of the program help patients adhere to their TB treatment, as well as what participants feel are the greatest benefits of the program, and

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<sup>1</sup> *Tuberculosis in China* (WHO), 2016

<sup>2</sup> *Tuberculosis in China* (WHO), 2016

<sup>3</sup> Hutchison et al., 2017

<sup>4</sup> Hutchison et al., 2017

what they feel could be improved or changed. Then 57 Zone was compared to other TB support programs around the world in order to provide further suggestions for improvement.

### **Program Overview**

Family Health International 360 is a USAID funded organization with the goal “to improve lives in lasting ways by advancing integrated, locally driven solutions for human development”<sup>5</sup>. In order to make the largest impact, FHI 360 combines evidence and knowledge with on-the-ground experience, creating a system where they are not only provide support for development, but also physically work to directly impact communities<sup>6</sup>. In China, FHI works with health and development issues in order to design new interventions as well as increase the demand and availability of health care services, particularly regarding HIV/AIDS and TB/MDR TB, which are two increasingly critical public health issues<sup>7</sup>. As part of their TB intervention, FHI has partnered with 57 Zone in order to combat the growing TB epidemic in China.

#### 57 天地 (57 Zone)

In December 2013, MDR-TB patients in Kunming established s social media group called 57 Zone based on QQ, a popular social network and mobile app in China with over 830 million users<sup>8</sup>. This group was designed with the goal of helping TB patients and their family members through the TB treatment process as well as helping them navigate the Chinese health system. The name of the group was chosen in order to motivate patients to adhere to their TB treatment, because in Chinese the number 57 is pronounced “wu qi” and sounds like “No giving

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<sup>5</sup> <https://www.fhi360.org/>

<sup>6</sup> <https://www.fhi360.org/>

<sup>7</sup> <https://www.fhi360.org/countries/china>

<sup>8</sup> *Mobile application provides support for tuberculosis patients in China* (2014)

up” and “I am healthy.” TB patients who join this QQ group can ask trained peer educators and/or health care workers questions about their health at any time, with many of their questions revolving around anti-TB medication, TB drug side-effects, nutrition and psychosocial concerns. Since its beginning, this single group has evolved into many different groups: the original 57 Zone for TB patients, one group for patients in TCC in Kunming, and one group for TB/HIV co-infected patients. All three of these groups have grown over time, with the original 57 Zone group boasting over 900 participants, 483 in the group for Kunming No.3 hospital, and 845 in the TB/HIV co-infected group.

57 Zone is comprised of seven different programs. The first are the QQ groups for patients, patients’ families, counselors, and FHI staff. The second is a hotline that anybody can call during working hours for assistance or to ask questions about TB. The third is one-on-one counseling for TB patients with a trained counselor. The fourth is small group education sessions, held twice a month about topics such as infection control, drug side effects, scientific treatment, diet, etc. The fifth is software for MDR TB patient management, where MDR patients can learn vocational skills and therefore be better prepared for life after TB. The sixth is a small financial aid fund for MDR TB patients. The seventh and final program is the baby formula project, where lower income TB patients with young infants can qualify for free formula.

FHI has two main goals for 57 Zone. First, they want the group to increase patients’ knowledge of TB. An employee of FHI stressed that knowledge of TB is very low in Yunnan, and this can cause many patients to stop taking their medication and also results in many misunderstandings of what TB is and how TB is spread. Second, they want the group to help patients maintain good adherence. Not only does the group serve as a convenient every day reminder to take TB medication, but also creates a community where patients can motivate each

other to take their medication and support each other through difficult times or uncomfortable side effects. So far, the program has made remarkable progress in achieving both of these goals.

### **Methods**

Most of the information in this paper was collected through interviews with 57 Zone group members and FHI employees. All people interviewed were told about my study and consented to being interviewed. Informants are also kept anonymous so as to protect their identity. The interviews were conducted in several different places, including the office of FHI in Kunming, Yunnan Tuberculosis Clinical Centre (TCC), and on the app QQ. The online method was used only to talk with QQ group participants who personally contacted me in a separate private chat. Information was also gathered through observation, including observations of the large group activities at TCC, as well as continuous observation of the online QQ group during the first two weeks of the study period. Finally, information was collected from online resources, mostly in the form of peer-reviewed papers or public health articles.

Four formal interviews were conducted in the first two weeks of the month of research, including one employee of FHI, one nurse associated with 57 Zone who worked at TCC, as well as two peer-counselors who worked both on the QQ group as well as with the in-patients at TCC. Each interview lasted at least an hour. All people interviewed were asked the same questions about what their role in the program was, what they believed the program was doing well, and what they thought needed improvement. Interviews and direct observation were the main way of information collection in order to personally get to know the people interviewed as well as to get to know the patients most affected by TB. A sample of interview questions can be seen in Appendix A.

The FHI employee was interviewed first in order to form a solid background on the program and TB in Yunnan, as well as to answer any basic questions at the beginning of the study. The nurse was interviewed in order to understand the role of a health worker both online and in the clinic, as well as to gain insight into the program from somebody who was not a TB patient. The two peer-counselors were interviewed in order to gain both the insight of somebody who has TB and the insight of somebody who is professionally involved with the program. They also provided great insight into the minds of patients both in the clinic and online as they are constantly interacting on a very personal level with other TB patients. In addition to the formal interviews, several informal interviews were conducted on the QQ app with TB patients who often participated on the online platform. These patients mostly provided information on what they thought the greatest benefits of the program were, as well as what they wish could be improved.

In order to record information during the interview, notes were taken on a computer. Zhou Yan, a teacher at SIT Study Abroad, translated all interviews from English to Chinese. In order to analyze the data most effectively, many papers regarding other TB group support programs were read in advance in order to better understand how to present the information collected during the study period. However, there were many shortcomings of the data collected. One, not enough people were interviewed in order to gain the fullest understanding of what needs improvement and what the program doing well. The few opinions expressed in this paper are no doubt a very small sample of the opinions of the people involved in this program. On top of this employees who were interviewed may have some bias towards making the program look its best, and therefore would have been more reluctant to suggest improvements. More actual participant interviews along with the employee interviews would have provided better feedback.

The third shortcoming is that not enough data was collected on how this program influences adherence. Needing to translate all the interviews was also not the most optimal situation, and because three in-person interviews were translated from Chinese, and many online interviews were also translated from Chinese, there could have been errors in translation and therefore no exact quotes were included.

### **Results and Discussion**

If there is one takeaway from this study, it should be that this group is doing incredible work and has received almost exclusively positive feedback from participants and employees alike. Common praise ranged from the changes seen within patients themselves as they went through this program, to the structure of the program and its overall management. One big reason for this positive feedback is possibly related to the fact that FHI is constantly working to improve and better their program. They are incredibly involved in the program, they are not just the financial provider but actually do hands-on work with the employees and participants, which create a healthy environment where everybody is contributing to making the program better. Through observation and interviews with staff and program participants regarding their opinions of what aspects of the program they feel are the most effective a few common themes emerged.

#### **What is 57 Zone doing well?**

The aspect of the program that received the highest praise was the in-person counseling sessions available to all participants. These counseling sessions are either lead by volunteer counselors or paid counselors, and are for both inpatients and outpatients. For some people, these sessions are more important than online counseling because of how personal they are, and how

they allow counselors to give the information face-to-face with the patients. This allows counselors to see patients' immediate reactions to the information given to them, which in turn allows the counselors to give a much more thorough and personal response to whatever problems the patient might be having. Their response can be much more thorough not only because of the immediacy of the response, but also because they can use resources beyond language such as books and diagrams and other physical materials to exchange information. In-person counseling also provides a space for extended discussion which is much more difficult online. One-on-one counseling is especially important when dealing with language barriers. Yunnan is home to twenty-five ethnic minority groups, some of who have their own language, which can create problems when trying to communicate important information about TB. One-on-one sessions provide a space where counselors can speak slow and clearly, and can even write things down if needed, all things that are more difficult to do in large-group settings.

Another common praise of one-on-one in-person counseling sessions for TB patients was that they are better for discussing private concerns. There are any number of subjects that may be uncomfortable to discuss either online or in larger group settings, such as certain side effects, family problems, mental health issues to name a few, and in-person counseling provides a space to discuss these issues. Where in larger groups it may be difficult for every person's voice to be heard, one-on-one counseling is an easier place for patients to share their own story and struggles with TB. Often patients' stories involve lots of hardship and a long road to being diagnosed and treated, and one-on-one sessions offer a more personal and private place to discuss these topics.

Observations at TCC also revealed there are significant benefits to larger group counseling sessions. Twice a month, TB patients and their family members gather at TCC in Kunming to discuss topics such as infection control, drug side effects, scientific treatment, diet,

etc. These groups provide a great opportunity for patients to exchange stories with each other, share common experiences, common struggles, and to make new friends. They also create a feeling of universality and cohesiveness, as well as feelings of hope and catharsis, so that patients no longer feel like they are alone in their struggles. Sometimes patients may feel ashamed of having TB, and joining the group and regularly discussing TB decreases some of the stigma surrounding it. The group allows TB to be normalized as a treatable disease.

A large group setting also allows counselors to spread a large amount of information to many people all at once, and then afterward test the patients to see if they actually absorbed the information they were given. This is extremely beneficial, because while online allows information to be spread quickly, there is no guarantee that everybody is actually reading the information or remembering any of it. Observations of one group session at TCC showed that when tested, patients were actually remembering the information given to them.

While informants acknowledged that in-person activities have significant benefits in regard to individualized counseling for each TB patient, they also acknowledged that online activities have a certain practicality and effectiveness that is equally relevant. Perhaps the programs most unique aspect, the online QQ group is a simple and effective reminder each day for patients to take their TB medication. Adherence is incredibly important for TB patients, as inconsistency when taking TB medication can result in drug resistant TB which is much more difficult and costly to treat, so the QQ group's importance as a reminder for patients to take their medication can not be stressed enough. Online is also a great tool for educating large amounts of patients all at once. Some patients may not attend the group sessions, or even if they do they may forget what they've been told, so online is an easy way for patients to access this same

information at any time of the day. Counselors are also available at all times of the day for any other questions they may have.

Counselors stressed that the online platform also benefits them. When a patient has a question the counselor may not have an immediate answer to, they can look up the answer or ask a health professional and then answer the patient's question. If the patient were to ask a question the counselor did not know at an in-person session, the counselor may have to refer them to a health worker or answer them next time they met, therefore online provides a quicker solution. Observations and conversations with group participants also revealed that a huge benefit of the online QQ group is that it is accessible to people all over China. Because this whole program is not available to any provinces besides Yunnan, Xinjiang, and Shandong, the online QQ group provides a space for TB patients and their families who live in other provinces to still get some of the benefit of the program.

When comparing the QQ group and the in-person counseling opportunities, it is clear that both serve important roles, and without one or the other there would be a significant decrease in the availability of health services as well as a decrease in the amount of people reached by these services. The QQ groups are an effective way to reach thousands of TB patients at once, where TB education is easily accessible and help for both mental and physical problems is available twenty-four hours a day. On this group one can make new friends, and through common struggles find motivation to adhere to treatment. The in-person counseling groups provide a private space for thorough, individualized help with a trained professional. Both of these programs are complementary, meaning where one may be lacking the other one fits the gap. For example, for many TB patients the online group may be a great way to communicate with other TB patients on a day-to-day basis, but during particularly difficult times or with private problems

the in-person counseling will be that extra support they need. It can also go the other way, where the online platform fills a gap in the in-person counseling. For example, many patients attend larger group meetings where they learn about their medication, the side effects, what they should eat, etc., but when they return home they may not remember all the details. Then when they need this information, they can go to the QQ group and all the information will be available to them. These are just a few examples, but they show the importance of both programs and how they complement each other.

Informants have also noticed a big change in the interaction between health workers and patients since the implementation of 57 Zone. One health worker said that before the program she just gave medical advice to patients and did not worry about what they needed besides medical advice. After the program was implemented, she began to see things from the patients point of view, stand in their shoes, feel what they are feeling, and now she understand what works for one patient may not work for another, and that it is important to work with the patient to figure out what is best for them. She now respects patients' choices, and will work to help them make the most educated choices they can. Another informant said that now patients also have much more respect for their nurses and doctors, and have an easier time communicating with them.

Improving health worker/patient relationship is especially important in China. In China, relationships between health care workers and patients can be tense, not only because many people do not trust their doctors, but also because doctors face an incredible amount of stress due the high volume of patients they have to see every day<sup>9,10</sup>. High levels of stress can be attributed to China's severe lack of doctors, and sometimes at larger clinics a doctor has to see a hundred or

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<sup>9</sup> *Doctor Shortage Hurts Communities* (2007)

<sup>10</sup> Jing et al., 2014

more patients a day<sup>11</sup>. This lack of trust has even resulted in violence, and it is not unheard of for patients to physically attack their doctors<sup>12</sup>. Consequently, improving health worker/patient relationships is of high priority in China, and 57 Zone has contributed to this goal. Patients involved with 57 Zone knew that the counselors and health care workers helping them through their treatment not only give them thorough medical advice, but also truly put their hearts into the work.

### Theories of group therapy

Looking at theories of what makes a successful therapy group can also provide some insights into what aspects of 57 Zone are most beneficial to TB patients. Group therapy is not a new concept; people have long been exploring the effects of group therapy to increase individual behavior<sup>13</sup>. Aristotle was one of the first people to begin to think about the effect of social interaction on individuals, and much later psychologists began to scientifically explore group therapy. In 1905, Joseph Pratt, a medical doctor in Boston, formed the first formally recognized therapy group with his TB patients in order for them to discuss their disease and to spread information, and recorded very positive results<sup>14</sup>. Group therapy continued to spread, and more research institutions were formed to study small group dynamics. More recently, Irvine Yalom, a key theorist for group therapy, developed eleven characteristics of group therapy that make it effective, which can be seen in Table 1. According to Yalom's theory, a therapy group that encompasses all of these factors provides the most effective and wholesome experience for participants.

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<sup>11</sup> *Doctor Shortage Hurts Communities* (2007)

<sup>12</sup> Jin, 2013

<sup>13</sup> Northeastern Society for Group Psychotherapy Foundation, 2015

<sup>14</sup> Rutan and Stone, 1984

Many of these characteristics are present in 57 Zone. For example, the online QQ groups are ideal spaces for developing universality, and to show patients on an every day basis that they are not alone in their struggles. They also foster interpersonal learning, where members can share their own stories and experiences in order to learn from each other. The online groups also create a “new family” where group members can feel heard and understood. The larger group meetings are models for development of social skills, where members can learn listening and public speaking skills. The peer-counselors are perfect models for imitative behavior, where new patients can learn from older patients who have gone through what they have, and become models of good TB patients. Many of these characteristics directly correlate with feedback from participants, who felt relief after they found a space to share their own story, or no longer felt alone, and as though they found new confidence to finish their treatment surrounded by people who were going through the same things they were.

Yalom’s eleven characteristics of group therapy	
Universality	“I am not alone in my struggles
Group cohesiveness	“Feeling belonging and value”
Catharsis	“Gaining relief from expressing emotions”
Installation of hope	“Confidence in effectiveness of group”
Imparting information	“Direct guidance from leaders”
Altruism	“Receiving through giving, helping others”
Corrective recapitulation of the primary family group	“A new family where group members can be heard and understood”
Development of social skills	“E.g. learning to listen, take turns, be empathetic”
Imitative behavior	“Group leaders as models for new behavior”
Interpersonal learning	“Learning from other members”
Existential factors	“Learning to recognize universal themes such as life and death, grief, love, responsibility”

Table 1: Yalom’s eleven characteristics of group therapy (Northeastern Society for Group Psychotherapy Foundation, 2015)

### What needs to be improved?

While there was a vast amount of positive feedback for 57 Zone, there were a few a few suggestions for improvements or additions. The most voiced concern was the lack of adequate financial support for patients, especially for patients who could not take first line TB drugs. In China, first line TB drugs are only free through the Center for Disease Control (CDC) system, and while some drugs are partially subsidized at TB designated hospitals, most still cost money. Along with this, it is the habit of many Chinese people to go to the local hospital for treatment, and very few know about the CDC, so most end up paying for their TB drugs. Patients also said that even if they took the free first line drugs, they had to take supplemental drugs that cost a lot of extra money. Informants stressed the reason drug prices are such a large barrier for so many TB patients is because many patients are from the countryside, or from poorer areas outside of Kunming, and so high levels of financial stress has lead patients to move back home and stop treatment. Stopping treatment is a huge risk factor for getting multi-drug resistant TB, which costs so much more than regular TB treatment because of the expensive drugs and duration of treatment. Providing financial support for poorer patients when they are first diagnosed with TB is particularly important in order to prevent MDR TB and higher costs in the future.

This is of course easier said than done. While in an ideal world this program would address all difficulties for patients, including financial difficulty, simply relying on this program to deliver all support to TB patients in Yunnan is unrealistic. That being said, FHI and 57 Zone have taken steps to make TB drugs more accessible to everybody, including establishing a fund for low-income MDR TB patients, and facilitating cooperation between the CDC and Chinese hospitals. While FHI is an international organization, some informants expressed desire that the

program work in cooperation with the Chinese government in order to provide better financial support for TB patients. One informant believed that financial support would not motivate many patients to adhere to their treatment and other forms of support were more impactful. Given that less than ten patients were asked questions about financial difficulty, and many different opinions were recorded, there are more than likely several hundred differing opinions on the subject in the larger 57 Zone program. In the wider world, there are thousands of opinions on this subject, and many different types of programs that are geared towards decreasing economic barriers to treatment. One such program with the potential to address the economic concerns expressed by the informants of this study is a voucher program.

Health voucher programs have had positive effects on many health systems all over the world. A health voucher program could have significant impact in Yunnan because voucher programs have the ability to improve areas in the Chinese health system that needs improvements. For one, a voucher program could reduce the cost of treatment for lower-income TB patients. Voucher programs have been shown success in targeting specific populations, and as the high cost of treatment is a huge barrier for lower-income patients in Yunnan, a voucher program could help lessen this economic pressure.<sup>15</sup> Secondly, a voucher program could increase the number of people utilizing important TB health services in Yunnan such as the CDC. Voucher programs have been successful in increasing utilization of health goods and services, as well as improving the quality of health services<sup>16</sup>. Third, voucher programs have been successful in increasing health awareness, which is especially important in TB patients, especially in places like China with a high population, packed cities, low knowledge of TB

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<sup>15</sup> Meyer et al., 2013

<sup>16</sup> Bellows et al., 2011

among the general population, and high rates of TB<sup>17</sup>. There is potential for a true impact in Yunnan as health voucher programs fit many of the gaps in the Chinese health system for tuberculosis.

Another suggestion from informants was an increase in the availability of counseling services. One informant thought that patients for whom the first line and second line drugs did not work needed extra counseling, and at the time being many did not have enough counseling opportunities. Some of this was attributed to the fact that there were not enough in-patient counselors at the clinic, as one informant said there were often too many patients to see at the hospital and not enough time to spend with each of them. Counseling is a very important part of the treatment process because it makes the patients much more confident to finish their treatment, as well as helps them to have a much better understanding of their disease. Without counseling, many patients could develop serious mental health issues such as depression, which makes patients much less likely to take their medication consistently or completely<sup>18</sup>. These irregularities can cause drug resistant TB or even worse, morbidity or mortality<sup>19</sup>.

Hiring a fourth inpatient counselor could benefit the patients so that each would receive an adequate number of hours each week of counseling and the counselors would not be so busy and rushed. Extra counselors could also be accepted on a volunteer basis to go into hospitals and share stories with in-patients in order to show patients that they are not alone in their struggles. Extra group sessions may also benefit many patients, and could help foster feelings of universality and a sense of community. A counselor could moderate these sessions in order to answer any big questions as well as provide group members with discussion topics and prepared

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<sup>17</sup> Meyer et al., 2013

<sup>18</sup> Khanal et al., 2017

<sup>19</sup> Sweetland et al., 2014

activities. There are only two group sessions a month at TCC, but with so many people attending them it is clear that they are popular and patients and their families are benefiting from them, so it would be extremely beneficial to offer more group activities. In order to make these sessions more convenient for patients as well as health workers and counselors, these meetings could be shortened to only an hour and could have fewer participants so to give more personal feedback to everybody in the group. More group sessions like the ones already held at TCC would be a low cost method of increasing the hours of counseling available to patients and their families.

Of the informants we interviewed, a few were worried about aspects of the management of the online QQ group. One informant thought that many of the participants in the QQ group were not actually talking about TB, and instead wanted to talk about other aspects of their lives such as relationships, television, etc. Through direct observation of the QQ group as well as conversations with online participants, it was evident that while many participants did not want to talk about TB, others were very eager to share their own stories and talk about the program. Having a space for both people who want to talk about TB and people who do not want to talk about TB is important, because even if somebody is not ready to talk about their disease the support system is still there for them when they become ready. One solution could be to have separate spaces for talking about TB and for talking about other topics. One page of the group could be discussions about TB lead by online counselors, answering questions and posting discussion questions, and then another page could be for other topics. This would make it easier for people to see what questions people are asking and be able to talk about topics that surround TB such as stigma, medication, side effects, jobs, diet, exercise. Separate spaces would allow those who want to talk about TB to not get pushed to the side by those who want to talk about non-TB related topics.

Expanding 57 Zone to other parts of Yunnan and other provinces was the most commonly mentioned suggestion for improvement. Informants said that because TB patients were from all over Yunnan two TB prevention centers in Kunming were not enough. While 57 Zone has spread to Shandong and Xinjiang, many patients online were from provinces other than these and expressed great desire for the program to be implemented closer to home. At the large group meeting, a few patients and family members of patients had come from Sichuan just to participate. One online participant was also very insistent that the program be implemented in his province Sichuan. From conversations with people living in other provinces as well as informants in Kunming, it was evident that the demand for 57 Zone in other provinces is high.

57 Zone has shown great success overall and has contributed to the lower rates of TB in Yunnan, Shandong, and Xinjiang by helping patients truly understand their disease, as well as by making them more confident to finish their treatment. The impact and influence this program has had on patients is invaluable, which makes it all the more important to expand this program to other parts of China. While implementing the whole program into a new place may be quite a difficult task, there are a few aspects of the program that could be more easily translated. Expanding the program within Yunnan could be a first step, where counselors from rural or hard to reach areas could be trained to lead small group sessions for TB patients who cannot come to Kunming. "TB clubs" have been shown to positively influence compliance with TB medication as well as social attitudes towards TB, and could be implemented by involving local health workers and training a few new counselors<sup>20</sup>. While it is thriving in its current environment, the TB situation throughout China is too large to be ignored and expanding the program to reach those who need it the most will require this program to grow and expand.

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<sup>20</sup> Demissie et al., 2003

### How 57 Zone influences adherence

One of the goals of 57 Zone is to influence patients to maintain good adherence, a goal that could ultimately help lower the growing MDR TB epidemic in Yunnan. 63,000 out of 1 million Chinese people with TB have multi-drug resistant TB (MDR TB), and as of 2015, China contributes one-third to the global MDR TB cases<sup>21</sup>. MDR TB is dangerous because it is much more difficult to treat than regular TB, and the treatment is not subsidized by the Chinese government so it is much more expensive<sup>22</sup>. There are many different factors contributing to the spread of MDR TB in China, but the largest factor is interrupted treatment. Studies have found that people who were previously treated for TB were more likely to develop MDR TB than new patients<sup>23</sup>. These people were treated for TB, but the unfortunate reality is that even when a patient has access to treatment, the difficult part is actually completing it. There are significant barriers to finishing treatment, and as a result China now has a growing MDR TB epidemic.

In order to actually motivate patients to finish their treatment and avoid MDR TB, certain barriers have to be addressed. Interviews were conducted in order to figure out how 57 Zone is addressing the problem of interrupted treatment, and in what ways it is influencing patients' adherence to their TB treatment. According to many informants, there are certain barriers to adherence that 57 Zone addresses, and other barriers that it does not. For example, while financial barrier was the biggest barrier to adherence for many patients, many informants felt that 57 Zone does little to address this barrier. Some informants wished that 57 Zone had financial aid programs, while other informants felt that simply relying on this single program to provide

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<sup>21</sup> *Tuberculosis in China* (WHO), 2016

<sup>22</sup> Hutchinson et al., 2016

<sup>23</sup> Yang et al., 2010

all TB services was unrealistic. While 57 Zone does have a small fund to help a few lower-income MDR TB patients, a majority of 57 Zone participants are regular TB patients who still suffer from significant financial difficulties.

Besides financial barriers, informants said the other significant barrier to treatment is the lack of TB knowledge among patients. Not knowing the risks of stopping their treatment, many patients will stop taking their medication when they encounter bad side effects, or will forget to take their medication after returning to work two or three months later. Informants felt that 57 Zone was doing a good job addressing this problem. As one of the goals of 57 Zone is to increase TB knowledge, there are many educational opportunities, both online and offline. Information on TB is available online 24 hours a day through articles and informational pamphlets posted by FHI onto the QQ group, as well as through the counselors who are always available to answer questions. Health workers are also available online at different times of the day to answer any questions patients may have. Offline also offers many educational opportunities, such as the small group activities or one-on-one counseling sessions.

Overall, there was not enough information collected to say if 57 Zone positively influences patients' adherence to their TB treatment. This is a complicated question because what is one person's greatest barrier to treatment is not the same for the every person, and measuring one barrier against another to say which is the greater barrier was not feasible with the little information collected. The only conclusion drawn with partial evidence is that 57 Zone addresses some barriers to treatment, and does not address others. The expansive support system 57 Zone provides is a positive step towards achieving their goal of motivating patients to maintain good adherence.

While some of these suggestions for improvements are quite broad, they are mainly for the purpose of offering a small insight into a few of the concerns of those involved in 57 Zone. The perspectives come from many different people and no doubt there are hundreds of more people with their own concerns or suggestions for the program. There is no one way to make a successful public health program, however, literature provides some insight into what characteristics make a health program successful. Looking at other programs around the world can also provide some valuable insights into what improvements would most benefit 57 Zone.

### TB Peer-Support Programs Around the World

While 57 Zone is unique in many ways, peer-support groups are not a new concept and there are many other TB patient support programs around the world that have proved to be effective ways of increasing adherence and morale in TB and MDR TB patients. Many of these group's successes can be seen to embody many of the same principles as Yalom's curative factors of group psychotherapy previously discussed in the section Theories of Group Therapy. One particularly interesting study by Demissiea, Getahunb, and Lindtjørn looked at "Tb clubs" in rural North Ethiopia, and studied how these clubs influenced compliance with TB medication as well as social attitudes towards TB. These TB clubs differ from 57 Zone in that they consist of exclusively in-person community meetings for TB patients, and are often supported by community leaders such as priests, religious leaders, or community elders<sup>24</sup>. This program has significantly impacted patients' compliance to their TB treatment, as well as shown significant impact on decreasing stigma towards TB patients within the community<sup>25</sup>. The TB clubs also helped to improve the relationship between patients and health workers, as well as reduced the

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<sup>24</sup> Demissiea et al., 2003

<sup>25</sup> Demissiea et al., 2003

fear of talking about their disease with family members or speaking of their disease in public spaces<sup>26</sup>

This program in Ethiopia shows several characteristics of an effective therapy group according to Yalom's theory. The TB clubs provide a space for interpersonal learning, as well as can foster feelings of universality. Participants can learn social skills from listening to other patients' stories, as well as catharsis, gaining relief from sharing feelings. The group can serve as a new family where each patient can feel accepted and loved, and can help install hope in participants. While 57 Zone shares many of these qualities, there is also much it can learn from these TB clubs and their approach to group therapy.

One unique aspect of the TB program in Northern Ethiopia was how it involved the community in the therapy and treatment process of TB patients. This helped to decrease stigma and eventually made it easier for patients to talk about their disease in public<sup>27</sup>. Involving the community in 57 Zone could have similar effects in China, and could help significantly reduce stigma against TB patients in Chinese society. While religious leaders were used in the Ethiopia program, this would not be as applicable to China, and instead different community leaders could be chosen, such as teachers, or local government officials. Typically these people would be respected in society in order to provide an example for community members to follow, and would be somebody who people listened to. Involving teachers in 57 Zone could be a bridge between TB patients and younger generations, and could be an effective way to educate students about TB and work to reduce any stigma and surrounding misunderstandings. Involving local government officials would not only benefit the community, but would also help show TB patients that they are not alone and be further motivation to maintain good adherence.

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<sup>26</sup> Demissie et al., 2003

<sup>27</sup> Demissie et al., 2003

The TB Action Group (TBAG) in the UK is another example of a successful TB support program. TBAG provides support for people during their treatment and recovery from TB, as well as helps raise awareness of TB and advocates for improved TB services in the UK<sup>28</sup>. While this program in the UK is not only a therapy group, its peer support program does have several characteristics of an effective therapy group according to Yalom's theory. Some examples of this are new feelings of universality and group cohesiveness, catharsis or relief from expressing emotions, interpersonal learning from other group members, and altruism or receiving through giving. While 57 Zone shares many of these same qualities, other aspects of the TB Action Group could provide unique additions to 57 Zone.

One unique part of the TBAG program is patients sharing their stories in the media or online in order to increase public awareness of TB<sup>29</sup>. A public awareness program in China could be very beneficial, as it was evident from interviews with informants as well as observation of the education session at TCC that more public awareness of TB is vitally needed due to the overall low knowledge TB patients have of their own disease. This kind of public awareness program using digital media has potential in China because not only is public awareness of TB low, but also digital media is becoming more and more a part of everyday life in China. Studies have shown that Chinese people are spending more and more time everyday on digital media sources such as smartphones, tablets, etc.<sup>30</sup> There are so many different media platforms that could be used to spread public awareness of TB in China, some examples being advertisements in public spaces, advertisements before online TV shows, or appearances on some of the hundreds of Chinese game or talent shows to name a few. TB awareness campaigns on websites

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<sup>28</sup> <http://www.tbalert.org/what-we-do/uk/tb-action-group/>

<sup>29</sup> <http://www.tbalert.org/what-we-do/uk/tb-action-group/>

<sup>30</sup> *Average Time Spent per Day with Major Media by Adults in China* (2016)

such as Baidu, China's version of Google with over 500 million total users, or Tudou, a very popular TV show watching website could be incredibly affective at reaching large groups of the population at once<sup>31</sup>. More TB patient stories in local news outlets, or posters at local bus stops could also increase public awareness. These are just a few ways 57 Zone could increase public awareness of TB, but it would not only benefit TB patients by helping lower stigma in the community, but increased TB knowledge could also help the general population protect themselves against further transmission<sup>32</sup>.

### Important Takeaways

What are the most important takeaways for improvements to 57 Zone? The first is to increase the abundance of services already offered to TB patients, whether that be expanding to other provinces, making counseling more accessible, more financial aid opportunities, and more in-patient peer counselors. Overall patients and employees of 57 Zone are happy with the content of the program, so happy that they want an increase in the abundance of what is already offered. The second biggest takeaway is while 57 Zone is helping TB patients themselves become more educated about TB, there is still a significant lack of TB knowledge nationwide that is only spurring the epidemic to new levels of severity. As long as TB knowledge is low, risk of delayed diagnosis and improper treatment are higher, which can lead to a more severe and deadly epidemic of MDR TB<sup>33</sup>. Suggestions for increasing educational opportunities in China are implementing more public awareness programs to increase overall knowledge of TB within the general population, as well as increase the opportunities for community involvement in 57 Zone,

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<sup>31</sup> Baidu Statistics, 2015

<sup>32</sup> He Liu et al., 2013

<sup>33</sup> He Liu et al., 2013

such as including local leaders to participate in group activities could help to decrease stigma and provide an example for community members.

### **Conclusion**

The main takeaways from this study show that there are some aspects of the program that are extremely beneficial to TB patients, and at the same time there are many places for improvement. Informants felt that the in-person counseling opportunities are most beneficial and impactful because of how personal the feedback can be, followed closely by the online QQ group because of its efficiency and the opportunity it creates for dialogue among TB patients. Suggested improvements included increasing financial support for patients, more in-person counseling opportunities, more peer-counselors, expanding the online QQ group, and expanding the program to other places beyond Kunming, Shandong, and Xinjiang. Some of these suggestions for improvements are quite broad as they are mainly for the purpose of offering a small insight into a few of the concerns of those involved in 57 Zone. Looking at other programs around the world can also provide some valuable insights into what improvements would most benefit 57 Zone. Some suggestions are adding more public awareness programs as well as increasing the opportunities for community involvement in 57 Zone, such as involving local leaders in group activities. Overall, 57 Zone is a unique program that has already had great success in educating and motivating patients to adhere to their TB treatment. With further improvements and review, this program can become a model for TB patient support programs all over the world.

## **Appendix A- Interview Outline**

\*Not all questions were asked, and alternate questions not listed were also asked, as interviews were relatively informal

### **Questions for NGO**

#### Background Information

- So part of your role in this group is actually being a participant, what does this mean?
  - Are you participating in all forms of the group, aka online/in-person?
- What was your motivation for supporting this program?
- Do you have goals for this group?
- Have you encountered any difficulties of working this program as an NGO in China with certain restrictions?
- How much do you directly work with the patients in this specific program?
- How involved are former or current TB patients in FHI as a whole?
- What do you feel the in-person sessions bring that the online simply cannot?

#### Question 1 (adherence):

- When you think about the Yunnan TB epidemic, what are the biggest challenges to adherence besides financial burden? AKA what are some of the most common reasons people stop taking their TB medication (for example they don't feel sick anymore, the side effects are too bad, no emotional support, etc.)?
  - Are these burdens addressed through this program?
- Which aspects of the group do you think most directly help a patient adhere to TB treatment?
  - Why these aspects?
- What difficulties to adherence do the group not address?

#### Question 2 (groups pros):

- What is unique about this group?
- What do you believe are the benefits of in-person group counseling versus just participating on the online platform
- What do you believe is this groups strongest aspect? For example, in-person peer counseling, TB education, online counseling, etc.
  - Why?

#### Question 3 (groups cons):

- What problems do you most often encountered online? In-person?
- If different, what problems to patients most often encounter online? In person?
- What aspects of the group need improvements?

### **Questions for nurses/doctors:**

#### Background Information

- What is your role as a health staff participating in this group?
  - ， 医务人员们在这个项目中扮演那些角色？
- Do you participate both online and in-person?

网络平台 and 线下咨询 (zilixun2) 小组的活动你都参加吗？

#### Question 1 (adherence):

- Are these patients taking their medication every day? How do you know?  
参加这个项目的患者们每天都按要求服药吗？你怎么确定？
- What is the biggest difficulty to adherence?  
持续(chi2xu4)治疗的最大困难有哪些？
  - What aspects of the group address this difficulty?  
项目的哪些方面反映了以上的问题和困难？
  - What difficulties do the group not address?  
有哪些困难本项目目前还不能照顾到？

#### Question 2 (groups pros):

- Is this group a good platform from which to educate patients about TB?  
本项目在对于患者们了解结核病的相关教育活动中是否起到了平台作用？
  - If so, what makes it effective? If not, what is preventing it from being effective?  
为什么是一个好的教育平台，或为什么教育平台的作用不大？
- What are patient's general mentalities before joining the group vs. after they join the group? Aka how do they feel about having TB before they join the group vs. after they join the group?  
可以比较一下患者们在参加相关活动(all related activities)前后的不同心里转台吗？
- How has this group affected the way patients interact with you?  
该项目的活动对患者们和你的互动(interact)有什么影响？

#### Question 3 (groups cons):

- What problems are most often encountered online? In-person?  
在线使用过程中，你常遇到的问题是什么？对于患者们呢？  
患者们在进行线下活动的过程中(process)，你常常发现那些问题？
- What aspects of the group need improvements?  
你觉得这个项目需要改进的方面有哪些？

### **Participants (interviews + survey?):**

#### Background Information

- Is having TB a burden? What makes it a burden (aka financial, inconvenient, stigma, work, healthcare system?)  
得了结核病是不是一个很大的负担？需要负担哪些方面？（比如经济负担，家庭负担，工作负担，健康负担？
- How much do you participate in the group? Do you participate every day, once a week, a couple times a month, only when you feel like you need it?  
你参加活动的频率高吗？是每天都参加，一个星期一次，一个月一次多，还是你觉得需要的时候才参加？

#### Question 1 (adherence):

- Have you ever missed a day taking your medication?  
你有过忘记服药的经历吗？
  - At the time did you know the importance of adherence?  
那时，你已经知道持续治疗的重要性吗？
  - How many days did you stop for?  
你多长时间没有吃药？
  - Besides financial barrier, what was your main reason for stopping? (Aka side effects, did not feel sick anymore, didn't think they were helping me, didn't have enough money, etc.)

除了经济负担以外，你觉得还有那些让患者放弃服药的原因？比如副作用让你不舒服，没有生病的感觉，觉得药物的作用不大，等等。

- What is the biggest difficulty to adherence?  
持续(chi2xu4)治疗的最大困难有哪些？
  - What aspects of the group address this difficulty?  
项目的哪些方面反映了以上的问题和困难？
  - What difficulties do the group not address?  
有哪些困难本项目目前还不能照顾到？
- Do you feel like the support you need to adhere to your medication is adequate?  
你觉得让你持续治疗的相关支持足够吗？
- What aspects of the group do you find most helpful for adherence (aka in-person sessions, online counseling, TB education, etc.)?  
你觉得项目的哪些方面对持续治疗最有帮助？（比如咨询小组，网上的咨询员，结核病的教育，等等）

#### Question 2 (groups pros):

- Is this group a good platform from which to educate patients about TB?  
本项目在对于患者们了解结核病的相关教育活动中是否起到了平台作用？
  - If so, what makes it effective? If not, what is preventing it from being effective?  
为什么是一个好的教育平台，或为什么教育平台的作用不大？
- What most benefits you of having in-person sessions? What are the benefits of online?  
项目的线下咨询小组的活动最大的好处有哪些？项目的网络平台呢？
  - Do you have a preference of which you use?  
你比较喜欢线下咨询小组还是在线活动？
- Do the in-person meetings fit into your schedule? Do you feel like there are enough in-person meetings?  
从你的日常安排中找到时间参加线下小组活动困难吗？你觉得咨询小组的时间足够吗？
- Do you post your questions online?  
你会在 57 天地的网站提出你的相关问题吗？
  - If no, what is stopping you?  
为什么？
- Do you feel like your knowledge of TB has gotten better/worse since joining the group?  
你觉得参加 57 天地以后，关于结核病的知识增加了吗？
  - Why?  
为什么？
- What are patient's general mentalities before joining the group vs. after they join the group? Aka how do they feel about having TB before they join the group vs. after they join the group?  
可以比较一下患者们在参加相关活动（all related activities）前后的不同心里转台吗？
- How has this group affected the way patients interact with you?  
该项目的活动对患者们的互动（interact）有什么影响？
- Did you know other TB patients before you joined the group? If so, did you find time to talk together about your experience?  
参加 57 天地以前，你认识的患者吗？如果认识你们也会常常分享治疗经历吗？
  - How did you emotionally and mentally feel before joining this group? After?  
参加这个项目前后的心理和情绪有什么不同？
  - If your mentality did change after joining the group, what aspect of the group do you think was most helpful (in-person, TB education, peer support, etc.)?

这个项目的哪些方面对于相关心理和情绪最有帮助？（比如线下咨询小组，网上的咨询师，结核病的教育，等等）

Question 3 (groups cons):

- **What problems have you encountered online? In-person?**  
在线使用过程中，你常遇到的问题是什么？对于患者们呢？  
患者们在进行线下活动的过程中（process），你常常发现那些问题？
- **Have you ever felt like you couldn't ask a certain question?**  
你有没有一些问题觉得不方便去问 57 天地的工作人员？哪些问题？
  - **Why?**  
为什么不方便？
- **Have you ever had problems contacting the staff of the website?**  
要直接联系 57 天地的工作人员们有困难吗？
- **What burdens to taking your treatment do you feel the group doesn't help address?**  
有哪些困难本项目目前还不能照顾到？
- **What aspects of the group need improvements?**  
你觉得这个项目需要改进的方面有哪些？
- **If you could add one thing to the program, what would it be?**  
如果你可以对这个项目做一个改变，那会什么？

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Future ISP Study:

- In what ways does being a peer- counselor for 57 Zone empower TB patients? Does it change the way they view their disease? In what ways?
- HIV/TB patients- looking at mental health of people co-infected with both HIV and TB
- The power of Chinese social media as a tool to increase public awareness of public health issues