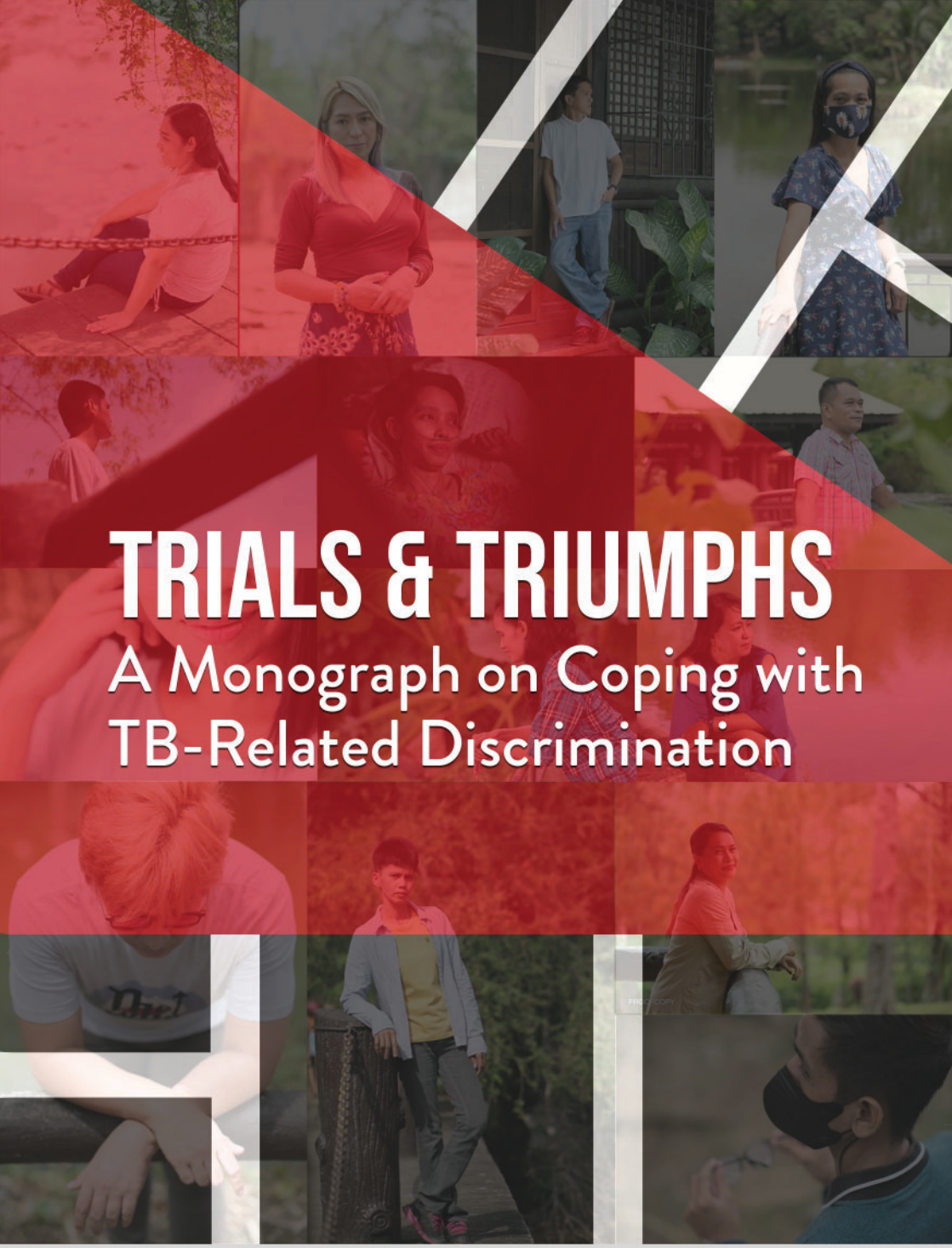

TRIALS & TRIUMPHS

A Monograph on Coping with TB-Related Discrimination

USAID FROM THE AMERICAN PEOPLE

ACHIEVE

PASTB Philippine Alliance to Stop TB

In partnership with the USAID from the American People

Writer: Alicia Lourdes De Guzman

Editor: Viola Torres
Lay-out by: Ron Vincent Delos Angeles
Photos by: JDM Studio Photo and Video Services

Action for Health Initiatives, Inc. (ACHIEVE)
Unit 201 Villasi Mansion, No. 160 N. Domingo Street,
Barangay Kaunlaran, Quezon City 1111 Philippines
achieve_hiv@yahoo.com
(+63-2) 83617980

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Association of Positive Women Advocates, Inc. (APWAI)

Breathe Free PH

Laban Lungs

Samahang Lusog Baga Association, Inc. (SLBAI)

TB Health Education and Livelihood Support Patients Alliance (TB HEALS)

Transpinay Association

And to the 15 brave souls who trusted us with their stories in the hope of contributing to the elimination of discrimination, we stand with you.

Maraming Salamat! Mabuhay Kayong Lahat!

FOREWORD

The first time I met a group of TB survivors, I was struck by their observation that there is stronger stigma on TB than on HIV. Having worked in HIV and AIDS for almost two decades, I am quite familiar with HIV-related stigma and discrimination and have been involved in the development of laws, policies and programs to address them. But right then, I realized I knew nothing about TB and the challenges faced by affected communities.

It's been five years since and although I will not compare the level of stigma between TB and HIV, the work that ACHIEVE has done with communities affected by TB proved that TB-related stigma and discrimination remain pervasive in Philippine society. The situational analysis that ACHIEVE conducted on the legal environment in relation to TB in the Philippines also showed a lack of legal mechanisms to address TB-related discrimination and provide redress to members of the community who experience them.

TB patients experience discrimination due to their TB status from people around them in their communities, in their workplaces and even in the healthcare facilities where they avail of services. Some continue to face discrimination even after they have been cured of TB. This monograph includes the accounts of 15 TB survivors who experienced various forms

of stigma and discrimination as a result of having TB. More importantly, the stories here reflect resilience, strength and perseverance to overcome the acts of discrimination they encountered. I hope that these stories inspire other members of the community to also be able to rise above the challenges that come with being diagnosed with TB.

For program implementers, service providers, policy-makers, and development partners, I hope these stories serve as a challenge to do better in ensuring that TB-related stigma and discrimination is eliminated while we work hard to end TB in the country. I hope for more investments dedicated to supporting community participation in all levels of decision-making in service delivery, programming and policymaking. There is also a need to invest resources to end TB-related stigma and discrimination through information and education, as well as social behavior change activities; and through local and national policy development to provide redress to members of the community who experience discrimination due to their TB status.

Lastly, this monograph is supplemented by a photo-exhibit that highlights TB-related stigma and discrimination to help raise awareness on this issue. This will launch a sustained campaign by ACHIEVE and USAID against TB-related stigma and discrimination. This campaign is only possible because of

the courage of the members of the Philippine Alliance to Stop TB (PASTB).

Amara Quesada
Executive Director
Action for Health Initiatives, Inc. (ACHIEVE)

ACRONYMS

ADR	Adverse Drug Reaction
AIDS	Acquired Immuno-Deficiency Syndrome
ARV	Anti-Retroviral
BHW	Barangay Health Worker
CBT	Capillary Blood Test
CHO	City Health Office
DOH	Department of Health
DSTB	Drug Susceptible TB
HIV	Human Immuno-Deficiency Virus
ISTC	International Standards for Tuberculosis Care
LCP	Lung Center of the Philippines
LGU	Local Government Unit
MDR TB	Multi-Drug Resistant TB
NTP MOP	National Tuberculosis Control Program Manual of Operations
OI	Opportunistic Infection
PGH	Philippine General Hospital
PMDT	Programmatic Management of Drug Resistant TB
PTB	Pulmonary Tuberculosis
PTSI	Philippine Tuberculosis Society, Inc.
RITM	Research Institute for Tropical Medicine
RHU	Rural Health Unit
SLBAI	Samahan ng Lusog Baga Association, Inc.
TB	Tuberculosis
TB DOTS	TB Directly Observed Treatment Short-Course
TB HEALS	TB Health Education and Livelihood Support Patients Alliance
TDF	Tropical Disease Foundation

BASHA

Feisty (*Mataray*) is most likely to be one's first impression of Basha. She's an out and proud trans woman, undeterred by societal norms. Entering a supermarket, she requested a security guard to address her as *"Ma'am"* and not *"Sir"* when he asked for her vaccination and identification cards. With her long, blonde hair and impeccable appearance, she stands out in a crowd.

Asked by what name she wanted to be known in this documentation, she answered without flinching: **Basha Rivera**, no attempt to hide her persona.

It seems she has always had a strong sense of self-agency. Growing up the third of four siblings in a crowded household, Basha remembers wanting her own space. Since that was not possible, Basha resorted to separating her personal belongings from those of the other family members.

Basha began asserting her independence in earnest upon completing high school. She took on any work from employers who would accept her, despite the lack of education and experience. She worked as a crew member in a fast-food outlet and all-around assistant in a beauty parlor. Eventually, she accepted an aunt's offer to send her to school in exchange for doing household chores. In 2009, she opted to live with friends. Young, healthy, and fit, Basha felt on top of the world. Until she developed a persistent cough.

Her friends noticed her rapid weight loss (*bumagsak ang katawan*). At their urging, Basha consulted a private

pulmonologist who diagnosed her with Pulmonary Tuberculosis (PTB). She started on the corresponding drug regimen for Category I (newly-diagnosed, smear-positive) PTB patients, a combination of rifampicin, isoniazid, pyrazinamide, and ethambutol. Basha felt encouraged by what the doctor said: after two weeks, she would no longer be infectious if she complied with the treatment regimen. She was resolute in her determination to take her medicines regularly. Basha did not experience any adverse reactions to the drugs at the outset of treatment and thought that there was nothing to it; that it would be a breeze (*carry lang*); and that she would be cured in no time at all.

But there was no improvement after two weeks or even two months. She was still coughing incessantly and used up rolls of tissue paper because she was expelling so much phlegm. (*Pakiramdam ko, tabu-tabo ang plemang lumalabas sa akin.*) She decided to consult another pulmonologist who advised her to keep taking her meds. Then she began experiencing the negative effects of the drugs: nausea, vomiting, hyperacidity. She could hardly keep anything down and completely lost her appetite. When she experienced vomiting blood (hemoptysis), the friend she was living with encouraged her to consult her child's pulmonologist.

The third pulmonologist observed that Basha was not responding to treatment as well as expected, leading him to recommend that Basha undergo a test. Basha turned out to be positive for the human immune-deficiency virus (HIV), so she was started on anti-retroviral (ARV) medicines and her

TB medications was adjusted accordingly, leading to a cured status after nine months.

Basha feels that she would have been cured sooner had she known of her HIV status when she was diagnosed with PTB. The TB medicines could have worked sooner if she had been able to take ARV medicines right away. (*Natulungan sana ng ARV ang TB meds.*) That is why she believes that clients who have TB should also be tested for HIV.

Her experience prompted her to actively participate in the Department of Health's (DOH) efforts to educate the public about HIV and opportunistic infections (OI) like TB. She has attained accreditation and is now a certified HIV counselor with her local government unit (LGU). She is asked to provide pre- and post-test counseling to clients who submit to HIV testing as well as to share her testimony in various public education and advocacy events.

Basha's story was featured on national television, eliciting mostly supportive and accepting reactions. She has had her share of discrimination and rejection, unfortunately, from people close to her, like a former boyfriend who was embarrassed that his officemates would find out and a cousin who "unfriended" her on social media. (*Kung sino pa ang ka-close mo, sila pa ang hindi maka-intindi.*) While she would like to correct all the misconceptions and mistaken notions that abound, she has learned to pick her battles and focus on people who are willing to open their minds. She shared some instances when she was discriminated against and how she dealt with these.

At Home

Basha was living with a friend when she was diagnosed with PTB. In fact, it was at the urging of her friend that she consulted a third pulmonologist because her condition did not seem to improve under her previous doctors. Her friend asked Basha to move to another friend's house, fearing for the health of her three young children. Basha did not take offense, knowing that children could get infected with TB from an infected adult. There were only adults in the house that she was moving to, so there would probably be a lesser chance of passing on the disease. This group of friends (*barkada/tropa*) provided the support that Basha needed to help her heal from the disease and recover her health. They sent her meals and fruits every day. (*Hinahatiran ako ng pagkain at prutas araw-araw.*)

In the Community

Basha alleges that TB patients are more likely to experience discrimination. "No one would know your HIV status unless you disclose it to them. If you have TB, you can't help coughing in public plus people immediately recognize the characteristics skeletal appearance and hunched posture of a TB patient. They try to move away from you." (*Mabuti pa ang HIV, walang makaka-alam sa status mo, unless mag-disclose ka. Hindi maitatago sa ibang tao pag may TB ka. Hindi mo mapipigilan ang umubo at pagtingin ng tao sa iyo, makikita ka nilang payat, buto't balat, nakataas ang balikat. Umiiwas sila.*) The changes in her appearance and the exclusion that came with

it had a great impact on Basha who had always been particular about her looks. But Basha learned to ignore these.

At the Health Facility

Basha started consulting a private physician for her persistent cough. She changed doctors three times, always preferring the services of private practitioners. Until she heard that professional fees, laboratory examinations, and medicines were free in public health facilities. She tried enrolling in a health center near her residence, but the health worker told her that she would have to start treatment from the beginning. Basha shuddered at the thought of prolonging the daily agony of nausea, vomiting, and struggling to eat, and decided she would rather continue and complete treatment under her private physician.

Insights & Recommendations

Basha is happy to note that today, patients who start treatment with private physicians can continue their treatment with the public health system after complying with laboratory examinations and documentary requirements. They do not have to re-start treatment. As well, the new International Standards for Tuberculosis Care (ISTC) and National Tuberculosis Control Program Manual of Procedures (NTP-MOP) offers testing for HIV in TB Patients and vice versa. In fact, Basha performed a capillary blood test (CBT) on her mother when she was diagnosed with TB in 2017.

While benefiting from developments in the clinical aspect, Basha notes that there is much to be done in terms of educating the public regarding TB prevention and control. Spreading information that patients are no longer infectious after two weeks of treatment can help people to understand that they do not have to avoid TB patients. There is a common belief that TB runs in families; that it is hereditary. Basha's personal experience would tend to support this belief, with a brother who had pediatric TB; her getting TB; and then her mother also getting TB. She would like to correct this mistaken notion, stressing that TB is spread by infection with the germs that cause TB (mycobacterium tuberculosis) and not by heredity. Educational efforts to help people understand that personal behaviors affect public health must be supported with local ordinances to facilitate behavioral changes. For example, people need to practice minimum health protocols (wear masks in public; wash hands frequently; and maintain physical distance from other people) and observe proper cough etiquette (covering mouth and nose when coughing; not spitting in public; disposing of used tissue properly).

There is no excuse for inflicting stigma and subjecting people to discrimination, but Basha opts to take the higher ground. She makes a conscious effort not to be offended and extends understanding to people who do not know any better. She says, "It's really up to you. What people say is not as important as what you think of yourself. You must accept yourself before you can expect other people to accept you. No one else can help you but yourself." (*Nasa iyo yun. Hindi mahalaga kung ano ang sinasabi ng ibang tao; mahalaga kung ano ang*

iniisip mo tungkol sa sarili mo. Tanggapin mo muna sa sarili mo. Huwag ka umasa na matatanggap ka ng ibang tao kung hindi mo tanggap ang sarili mo. Walang ibang tutulong sa iyo kung hindi mo tutulungan ang sarili mo.) She has charted her own course, turning the double whammy of HIV and TB to her advantage, paying it forward by using her own experience and training to help other in the same situation.

BRYAN

Bryan is 35 years old, a case manager for a non-government organization (NGO). He is effective in convincing clients to adhere to treatment protocols despite the difficulties, precisely because he has experienced these: he persisted, and he was cured. He says, "Even if you're infected, you don't have to be afraid. You will be cured if you just obey the doctor's instructions." He serves his clients dutifully, accompanying them for checkup and laboratory examinations, encouraging them every step of the way. This is how he thanks the people who were there for him when he was at his lowest.

Bryan describes himself as a tuberculosis (TB) survivor who is now in a stable condition. He was not surprised when he was first diagnosed with TB in 1998, as his grandfather died from the disease and his father recovered from TB. He consulted a private physician because of rapid weight loss. His x-ray showed that he had TB. He began taking the medicines that the doctor prescribed. But it was such a bother to take them, and they were quite expensive so he would stop taking them whenever he felt better. No one explained the dangers of developing resistance to the drugs resulting from this practice. (*Ganun dati sa private – reseta lang; walang explanation.*)

Bryan was diagnosed with Multi-Drug Resistant TB (MDR TB) in 2017. The City Health Office (CHO) provided his medicines, but he had to go to the health center for his daily injections. The pills were large and difficult to swallow. They left a metallic taste in his mouth (*lasang bakal*) and Bryan lost his appetite. The drugs are supposed to be taken on an empty stomach, so Bryan would

wake up at 5 a.m., take his medicines, and go back to bed to try and sleep off the nauseated feeling.

At the Health Facility

When he woke up again at around 8 a.m., Bryan would go to the health center to refill his medicines and have his injection. He tried to be at the health center ahead of other patients. On a day when he was feeling particularly bad, he woke up late and also arrived late at the health center. There were already many mothers and babies ahead of him. The health worker admonished him: "It's not the schedule for TB patients now. Stay outside. Do not come in because you might infect the staff and other patients." (*Hindi schedule ng TB ngayon. Huwag kang papasok; baka mahawa mo kami.*)

Mortified, Bryan swore that he would never go back to that health center again. He taught himself to administer intra-muscular (IM) injections by watching instructional videos on YouTube. He completed his treatment this way.

At Home

Even if Bryan's family had previously experienced TB, Bryan immediately separated a set of utensils for his exclusive use. He confined himself to his room, coming out after everyone had finished eating, to eat his meals by himself.

Insights and Recommendations

Bryan feels that more recovered patients should be recruited and organized to support those who are undergoing treatment, especially the new ones. He suggests that health workers undergo training to be more considerate of clients' feelings and not berate them, especially in front of other people. The clinic schedule should be posted outside health centers so that patients know when their specific concerns can be served without detriment to other clients. Health systems and procedures should facilitate access to health services and promote health-seeking behavior. For example, a TB patient should be able to acquire medicines where it is convenient for them, and not just from one facility. The health system should continue to monitor "cured" patients through GeneXpert tests every six months to detect any reinfection and start treatment soonest.

FLAX

She goes by the name Flax, a moniker given by her high school peers (*barkada*). One inevitably associates her with flax, one of the very first plants domesticated by humans. Flax has been cultivated for thousands of years: the fiber is used to make cloth, rope, and paper; the flowers for dye; and the seeds for food and oil. Just like her hardy namesake plant, Flax is a survivor.

Flax has a degree in banking and finance and a teaching certificate. She works in the local office of a national government agency. Flax is in a consensual union with a batchmate from collage. He is a senior supervisor in one of the largest agricultural companies in the country. Flax quips, "My live-in partner is also is my treatment partner." They have a son who is now eight years old. When Flax was diagnosed with Pulmonary Tuberculosis (PTB), she and her family had all the children in the family compound undergo a skin test for the disease. Mercifully, none of them had a positive result.

Flax was working in a big mall when she developed a persistent cough. She consulted in a private hospital and was found positive for Drug-Susceptible TB (DSTB). Her bosses advised her to resign so she could rest and recover faster. She decided to move back to the province where she lives with her nuclear family and close relatives. Monitoring and management of her case was transferred to the City Health Office (CHO) closer to her place of residence. Her treatment partner would diligently make the more than one hour commute to the CHO where the staff would issue medicines for one week. With strict adherence

to the treatment protocol, the support of her family, and rest, Flax achieved "cured" status after six months.

At Work

Flax resigned from her job upon diagnosis and did not work for the entire six months that she was undergoing treatment. She had a difficult time finding work even after completing treatment and being cured. She grabbed the opportunity to work as the substitute of a government employee who was going to leave. Eventually, she applied for a position in that same government agency but at a different local office. She completed all requirements for application and attended the scheduled orientation. At the end of the day, the one conducting the orientation asked the applicants to submit to a medical examination on the following day. She said that the applicants would be accompanied by the office nurse to ensure that no one tampered with the results of the medical examination, especially the chest x-ray. She commented that applicants with TB would be at disadvantage. (*Paubanan nako kamu sa nurse kay dili ko ganahan nga naay TBhon diri.*) Flax did not pursue her application.

At the Health Facility

Flax had begun coughing again and consulted a physician who advised her to undergo a GeneXpert test at the CHO. When she got home, she began coughing uncontrollably until she

vomited blood and had to be admitted to a private hospital. Her GeneXpert test showed her to be positive for TB with resistance to rifampicin. The TB Directly Observed Treatment Short-Course (TB DOTS) facility coordinated with the private hospital for the proper management of the Multi-Drug Resistant TB (MDR TB) case. Flax could not grasp what was happening. She thought that she was cured of the TB, but now, she was sick again with a worse kind of TB. The nurse tried to explain what MDR TB was and what needed to be done, but Flax could not comprehend anything. Much later, she was able to accept her situation and agreed to go to the provincial hospital for diagnosis and treatment. She underwent laboratory test and physical examinations to determine the appropriate treatment for her. The nurse went out of her way to help her, and they remain text mates to this day.

Flax was "decentralized" to a health center where all the patients who fl ocked there for various health concerns were attended to by a single midwife. The midwife did not invite Flax to enter the center but instead directed her to sit at an open shed (*kubo*) which was located just beside the entrance to the health center. Inherently good-natured, Flax did not even think she was being discriminated against (*Wala ko naghuna-huna nga dautan to*). She thought that was just the way things were done at that health center. The midwife said she would visit Flax at home, but after a few days with no visit from the midwife, Flax decided to go back to the health center. Again, she was ordered to wait outside in the open shed. This became the routine: Every day, the midwife administered the injections for Flax in the *kubo* in full view of

everyone in the area. During the times when injections had to be made in the buttocks, the midwife asked Flax to pull down her pants without providing drape or any other covering. (*Kon sakit pa ug gahi na sa bukton, gipa-hubo ko kay sa lubot mag-injection.*)

On days when the midwife had to be away from the health center, Flax had to go to wherever she was to get her injection. (*Mag apas-apas kon asa siya niadto.*) Flax was also given her medicines in bulk, and she had to be the one to prepare her medicines and take them on her own without supervision. (*Kasukaon na ko bisan ga segregate pa sa mga tambal.*) There were times when Flax decided to travel to the city to have her injection done in a private hospital, even if she had to pay for it. She exclaims, "Thank you Lord, I still got my injections (*nakapadayon*)!" She knows she has been very fortunate to be able to complete treatment, aware how others would just have given up, unable to endure the adverse drug reactions (ADR) on top of dealing with indifferent health workers.

When Flax had to spend an extended period in her partner's hometown, she had to transfer to the health center there temporarily. This was when she realized how shabbily she was being treated in her own locality. Upon arrival, she was cordially invited to come into the health center and the health worker listened intently to what she had to say. The health worker then directed her to a room where her injection was administered in private. The health worker was available even on weekends. Still, Flax generously grants that maybe, the health worker in

the other health center was not properly oriented, that she had more patients to attend to, that is why she tended to be curt with patients. (*Basin wala na orient ug tarong. Loaded kayo, daghay gui atiman.*)

Insights and Recommendations

Flax suggests that health workers be given an in-depth orientation about TB and other health concerns that they treat. Health workers should have empathy for clients who are already dealing with physical discomfort and accompanying feelings of inferiority. For others who might find themselves in similar situations, Flax offers words of wisdom borne out of her own experiences: "It's not your choice that you are sick, but you must deal with it. Accept your situation. Get treated so that you will not continue to spread the disease, especially to your own family." (*Dili nimo choice nga niabot ang sakit. Dawaton na lang, ug manambal para dili na matakdan ang uban, labi na ang familia.*)


Psycosis
NAKA
KAYA
KO
MONTH
OF
TREATM
MY
FUTUR
LORD.
WHY
ME
??
NON
SMOKE
NAKAKAHI

JB

His story was featured in a popular news program to mark Lung Month in 2019. This led to an altercation with his brother who accused him of bringing shame to his family. Rather than take offense, JB took the opportunity to share some facts about tuberculosis (TB) to broaden his brother's understanding and support for TB patients. Their mother had succumbed to the disease after all.

JB is one of four siblings. They used to live in Metro Manila where his mother was a seamstress (*mananahi*). She was so preoccupied with earning a living that she neglected to take care of herself. She received treatment for TB at the health center but did not take her medicines consistently. She would stop taking her medicines whenever she felt better. When she became too ill, the family moved to her home province. After she died, the family found out that she had not been taking her medicines. It was like she had given up the struggle to regain her health. JB's father moved back to the city with his two daughters while JB and his brother remained in the province with their grandmother.

JB was in third year high school, looking forward to attending his junior-senior prom. He went with friends to shop for clothes, but he began vomiting blood. He had been ignoring an incessant cough before this. A relative saw him and encouraged him to seek medical attention. He consulted a private physician who prescribed medicines. JB took four types of pills for the first three months. This was reduced to three, and then two until the end of six months. JB had a difficult time complying

with the treatment as he had to walk for almost three hours to obtain the medicines and walk back home again.

When he was in first year college, JB experienced hemoptysis again. He consulted a private physician and was placed on the six-month treatment course. This time, JB resolved to adhere to the treatment regimen and completed the treatment. In his third year of college, JB was trying to comply with the requirements to maintain his scholarship. He ran to get to the school cashier before closing time and experienced massive bleeding. He was diagnosed with acute gastrectasis at the emergency room until JB informed the hospital staff of his history of TB. They recommended a GeneXpert test, but this was not available in the province.

His father decided that it would be better for JB to seek treatment in Manila. JB consulted in a private hospital and was prescribed a TB drug for six months. Although he complied with treatment, JB felt that his condition did not improve. He went for a checkup at the Research Institute for Tropical Medicine (RITM) where he tested positive for Multi-Drug Resistant TB (MDR TB). He was referred to a health center closer to his residence where he began treatment. JB says it was like being in a different world with all the side effects that he experienced: vomiting, loss of hearing, joint pains. (*Para kong nasa ibang mundo: suka, pagkabingi, sakit ng kasu-kasuan.*) There were times that he could not find a comfortable position to sleep because his arms and buttocks hurt from being like pincushions from all the injections. He could not even hoist

himself up a jeepney because of the pain in his joints. He considered throwing himself in front of an oncoming train.

The Tropical Disease Foundation (TDF) endorsed JB's participation in a program in the Lung Center of the Philippines (LCP). He was amazed at how staff and other patients showed love and affection for each other like a big, extended family. He realized that not all TB patients were skinny because he met chubby people who were also TB patients; that anyone could have TB, rich and poor alike. There were patients who were students, businessmen, call center agents, doctors, and nurses. JB's heart was moved when he saw babies and young children struggling with the treatment. He thought that if these innocents could complete treatment, so could he. He resolved to do whatever it took to be cured to honor his mother's memory.

JB was certified "cured" in 2011.

Insights and Recommendations

Paradoxically, JB thinks that maybe, his getting TB was a good thing. He could have been just another feckless young man but having TB and being cured taught him many life lessons. He is grateful to all the health workers and his peers for all the care and encouragement they gave him. He believes he owes it to them to pass on the love and support to others who are enduring the difficult treatment. He feels most especially for pediatric patients, extending care to them as he would to his

own siblings. He exerts effort to try and make taking medicines easier for them by pulverizing the pills and, yes, adding a little bit of sugar to make the medicine go down.

He suggests widespread information dissemination to help the public understand that they can help prevent the spread of TB by practicing healthy behaviors like cough etiquette, not spitting just anywhere, and ensuring proper ventilation at home. Most importantly, everyone, particularly family members, should accept TB patients and support them in their journey to back to health.

LA

LA is the eighth of nine children of a farmer. Seeing how hard her father worked to support the family, LA took it upon herself to stop schooling after finishing fifth grade. Instead, she helped her father earn a living. Now 46 years old, LA has two grown up sons from a previous relationship. Three years after her partner died of leukemia, she entered another relationship. She and her current partner now have three children aged 15, 12, and 7 years old. LA is a subcontractor for a shoe manufacturer. She is an "assembler", meaning she puts shoe parts together. She feels this work-from-home arrangement is advantageous, allowing her to supervise her children's schoolwork, at the same time augmenting the earnings of her partner, a tricycle driver.

At Work

In 2009, LA worked in a shoe factory where she was required to undergo a chest x-ray and medical examination every six months as a condition for contract renewal. Shortly before she was due to renew her contract, the company's secretary saw her vomiting blood. She advised LA to go for a checkup. LA soon observed her co-workers whispering to each other whenever she was around. They no longer invited her to join them during lunch break. Spunky LA told them off: "Sickness can be cured, but there's no remedy for bad behavior." (*Ang sakit nagagamot, pero ang masamang ugali, hindi.*) She left the factory and never looked back despite the owner's assurance that he would rehire her when she got well.

LA first went through a six-month treatment course at the health center and then another eight months with injections

which she had to pay for herself. But she did not get any better. She kept vomiting blood. She rued the effect of her illness on her comely appearance. She lost so much weight; her own family could hardly recognize her.

In 2013, LA consulted at the Lung Center of the Philippines (LCP). Here LA realized that anyone could get TB – young or old, rich or poor. The patients bonded together on their journey to regain their health. LA was encouraged to go through the treatment and be cured, even though she would have to really work hard at it. The health worker carefully explained the process to her. Former patients were also there to support those who were starting treatment.

Doses of medicines are computed based on the body weight of the patient, hence, LA had to take 15 pills and one injection daily. She would commute to LCP every day bringing her own juice and food. Adverse side effects of the drugs she was taking hit her hard on the seventh month of treatment. She lost her hearing, became very moody and experienced hallucinations. She heard voices inside her head pulling her in opposite directions: "Take your medicines/ Don't take your medicines." One time, she jumped over the wall behind their house. It was a good thing she did not injure herself. She is grateful that the health workers in LCP were always supportive. She was immediately referred to a psychologist. Other patients and volunteers stayed with her through her struggles. *(Hindi ako pinabayaan. Nagsasama-sama para maitaguyod ang gamutan.)* After 18 months, LA was certified "cured" in 2014.

In the Hospital

When LA started treatment, she was advised to avoid getting pregnant as pregnancy might make her treatment more difficult and affect both her health and that of the baby. Nevertheless, when she did get pregnant, the staff at LCP assured her that they would be more vigilant to ensure her and her baby's health. It seemed to LA that the baby could sense the unusual circumstances of her gestation. When medication time approached, LA could feel the baby becoming agitated in her belly; eventually quieting down when the side effects subsided. One day, after LA took her medicines, labor contractions started and then her water broke. LCP is not equipped to handle deliveries, so a fellow patient accompanied LA to a nearby hospital. However, the staff at that hospital asked them to transfer to yet another hospital for fear of spreading infection to other patients. LA could not convince the staff to let her stay even though she assured them that although she was undergoing treatment, she was already negative and no longer infectious. Fortunately, a taxi driver agreed to transport them to a third hospital where LA delivered her daughter. LA thought it would be futile to file a complaint. She was just grateful for the safe delivery of her healthy baby, who is now seven years old.

Insights and Recommendations

LA has these suggestions based on her own experiences: Patients should learn to accept their illness because it is not their fault. They should seek a medical consultation as soon as

possible. Asking for help should not be seen as embarrassing. People are willing to help, but patients need to ask for what they need. Patients should also be responsible for complying with treatment. When cured, ex-patients should encourage others who are struggling to complete treatment. (*Tanggapin mo muna ang sarili mo para matanggap ka ng iba. Magpa-checkup agad para magamot agad. Huwag mahiyang humingi ng tulong para matulungan. Maging responsableng pasyente at huwag sayangin ang pagkakataon na magamot. Tulungan ang iba na makumpleto ang gamutan.*)

All hospitals should be prepared to accept patients – regardless of other conditions, like infectious disease – especially in case of emergencies.

LEM

He always wanted to be a nurse for as long as he can remember, belonging as he does to a family with many members in medical professions. He obtained his bachelor's degree from a well-known university and is a Registered Nurse (RN). He graduated in 2013, at a time when nurses from the Philippines were in high demand all over the world and, consequently, many students enrolled in nursing. There were so many student nurses that they could not all be accommodated for clinical practice in hospitals. Students had to pay to be able to work as "volunteers" in hospitals. Those like Lem who performed well were offered a second round of "volunteer" engagement that allowed them to choose a specific area of practice; for example, the operating room. If they continued to perform creditably, they would have to keep paying to "volunteer" again and again until such time that a position opened for regular hiring. Lem opted out of these frustrating and oppressive arrangements. He attempted to find a regular position in other hospitals but was rejected more times than he could recall. There were just too many nurses vying for limited positions.

Dejected, Lem applied for a call center job on a whim and was hired on the spot. (*Nakita ko lang yung sign and nag decide ako mag-apply*). However, this job involved working odd hours, turning night into day. Lem's health deteriorated. He developed sores on his neck that oozed pus. He experienced what he refers to as the "cardinal" symptoms of tuberculosis: weight loss, fever, chills. One time, his team leader saw him vomiting blood. He called Lem aside and advised him to have an HIV test and take a medical leave to regain his health.

When he worked as a nurse, Lem regularly saw posters encouraging people to get tested for HIV. He admits to ignoring these reminders even though he knew he should get tested. Eventually, he found a clinic far from the province where he lived, in a part of the metropolis not frequented by anyone he knew. He tested positive for HIV. He was advised to take a confirmatory test at the Research Institute for Tropical Medicine (RITM) in Alabang, Muntinlupa City. His HIV positive status was confirmed, and the counselor encouraged him to disclose his status to his family. His whole world had come crashing down, but still Lem did not disclose his status to anyone. Neither did he seek treatment.

At a family reunion during the holidays, one of Lem's cousins, a doctor, commented on his gaunt appearance and suggested he take an HIV test. That was when Lem broke down and finally confided in someone. Unfazed, his cousin asked if he needed help disclosing his status to the family. Encouraged, Lem decided to tell his family. To his great relief, he was not met with the disdain and rejection he feared; rather, they hugged him and assured him of their love. Lem had lived for years without treatment for HIV and TB. He was so weak that he no longer wanted to seek medical help. But with his family solidly behind him, he was convinced to seek treatment. Lem drew strength from his family, especially his mother who faithfully accompanied him to treatments despite her old age.

Lem's family had to request for the use of the barangay ambulance to transport him to San Lazaro Hospital in Manila. He was diagnosed with extra-pulmonary TB and Multi-Drug resistant

TB (MDR TB), opportunistic infections of HIV. He needed to recover his strength and increase his CD4 count before he could start on Anti-Retroviral (ARV) medication. He was advised to start treatment for TB in a government hospital closer to home. To spare him the daily trips to the hospital, the health workers arranged to give Lem a full month's supply of medicines through a satellite clinic.

In the Community

Upon his return home, Lem could not help but notice the sly glances from neighbors. They looked at him furtively and whispered to each other. Some even made sure that he overheard their comments about how he was a nurse and yet had supposedly gotten AIDS. (*Nurse yan, pero tingnan mo... may AIDS.*) Many of them knew that he had been ill and had been in the hospital, even though Lem had disclosed his status only to his family and he was certain that none of them had talked about it with the neighbors. Lem traced the gossip to the driver of the ambulance who brought him to the hospital. Curious neighbors had asked him about the trip. The driver divulged that he had brought Lem to the H4 Pavilion of San Lazaro Hospital, the dedicated ward for HIV, leading the curious to conclude that Lem had AIDS.

Rather than harbor ill feelings towards those who gossiped about him, Lem took the opportunity to educate them about HIV and AIDS. He cited his own experience to show that anyone can have HIV, but that having the virus is not a death sentence. Lem says,

"You can live a long, productive life for as long as you get the proper treatment and care."

At the Hospital

Lem strictly complied with the regular laboratory tests as requirement for patients enrolled in the Programmatic Management of Drug-Resistant TB (PMDT) in a hospital. As a nurse, he knew how important regular testing is to ensure that patients receive the appropriate medicines. He fasted on the nights before his scheduled laboratory examinations and made sure he arrived promptly at the hospital. One time, he signed in the logbook at 7:20 a.m. and proceeded to the laboratory for blood extraction. The medical technician on duty looked at his request and asked him to wait outside. Lem followed up his request after a few minutes, anxious that he would exceed the required time for fasting. True enough, the medical technician told Lem that he had over-fasted and that he would have to come back another day. Lem tried to explain that he had arrived on time and had been waiting for the medical technician to attend to him. Dismissive, the medical technician told him that he was not a paying patient anyway. (*So? PMDT ka naman. Hindi ka nagbabayad.*) Lem was incensed at the medical technician's behavior. Out of pique, he immediately relayed the incident to his aunt and cousin, both consultants at the hospital. He went home and wrote an incident report which he presented to hospital administration. Other patients supported his move, some of them relating that they had missed examinations because they were intimidated by the medical technician.

Insights and Recommendations

This incident taught Lem that patients should not be afraid to speak out when their rights are being ignored. Patient education should include discussion of patients' rights and responsibilities so that they can assert their rights and fulfill their responsibilities. Institutions should establish structures and systems to ensure that patients are able to enjoy their rights; for example, by setting up a clear grievance process with specific steps and assigned staff. Moreover, Lem noted that there can be strength in unity: Patients raising their concerns collectively validates the issues and lends credence to the complaints. A group of people is not as easily dismissed as just one person. At the same time, patients do need to be mindful of their responsibilities. They need to be considerate of others, including the health workers who serve them. Patients must be careful not to spread the infection by wearing masks, practicing cough etiquette, and most importantly, not spitting just anywhere.

Lem believes there must be a reason why he has regained his health, that he was given a new lease on life to fulfill a mission for others. (*Siguro, may dahilan. May mission na dapat gampanan para makatulong sa iba.*) That is why he takes every opportunity to reach out to other people, even those who maligned him at first. He hopes sharing his experience and knowledge will steer others back on the road to health. He advocates reaching out to families of TB patients to help them understand how to support their sick family members. Above all, he says, "Don't lose hope." *(Huwag mawawalan ng pag-asa.*)

Lem participates in TB Health Education and Livelihood Support Patients Alliance (TB HEALS), a support group of MDR TB patients and their families. TB HEALS was organized by the TB nurse coordinator at the hospital where Lem underwent treatment for MDR TB. He observed that many patients do not avail of treatment even if it is free because they still do not know about it, and they do not have the support of their families. The group advocates for upholding patients' rights and raising public awareness that TB is preventable and curable. They also plan to engage in economic activities to generate funds for medical and hygiene supplies of patients. Although activities have been put on hold due to constraints imposed by the Coronavirus disease (COVID-19) pandemic, TB HEALS hopes to pursue these when restrictions are lifted. Their motto is: "It is our passion to serve with compassion."

MARIA

Maria is 29 years old and a graduate of a vocational course. She works as staff in a small business office. Her partner for almost eight years now is 35 years old and works in a t-shirt printing shop. Together they have two children: a daughter who is six years old and a son who is five years old. Both attend nearby schools.

Maria's first pregnancy was uneventful, and she found herself pregnant with her second baby five months after her first delivery. She sought prenatal care at the health center. Fortuitously, HIV testing was being done at the health center on the day that she went for her checkup. Waiting for the HIV test results felt unnerving as, one by one, results were released to the women waiting with her. The staff asked Maria to come into a room to reveal that she had tested positive for HIV. She was informed that her specimen would be sent to a higher-level laboratory for confirmation and that it would take around two weeks to get the results. The health worker tried to explain that HIV testing was being conducted so that if any of the pregnant women tested positive, they could be treated immediately for their protection and that of their baby. At this point, Maria could no longer understand what the health worker was saying. She was crying uncontrollably.

Distraught, Maria shared the dreadful development with her father. Maria had always been a Papa's girl and it so happened that he was there when she arrived home. She said her father became angry at her partner, thinking he was the one who had infected his daughter with HIV. (*Nagalit. Ang naisip niya, yung asawa ko ang nakahawa sa akin.*) To his credit, her partner took

the news calmly. He reminded Maria to go for regular checkups and to obey the doctor's instructions. He would eventually test negative for HIV. Maria says her HIV status has never been an issue between them as a couple.

The health center staff visited Maria at home with the results of her confirmatory test and then accompanied her to an HIV clinic where she underwent further counseling. Then the staff took her to the Philippine General Hospital (PGH) which was going to be her treatment hub.

Before she could start on anti-retroviral (ARV) therapy, Maria lost weight rapidly. She developed fever and had difficulty in breathing. She tested positive for tuberculosis (TB) and was prescribed anti-TB medicines. After two weeks on the anti-TB medicines, she began ARV therapy. She took the anti-TB medicines in the morning and the ARV in the afternoon. PGH provided the ARV, but unfortunately, the anti-TB medicines she needed were not available in PGH at that time. Maria had to buy TB medicines for the entire nine-month duration of her treatment.

Maria delivered a healthy baby boy via caesarian section in PGH. Her son was given pediatric ARV and isoniazid for one month after birth. Her partner's mother took care of the baby upon discharge from the hospital, thinking it best to separate mother and child to avoid infection. For the same reason, she also asked her son to consider living apart from Maria while she was undergoing treatment.

Maria was declared "cured" of TB in 2017. Maria tries to live a healthy lifestyle, avoiding alcoholic beverages, getting enough sleep, and taking vitamin supplements. She commends the health workers of the health center and PGH for their solicitous care and for the supply of milk and vitamins. Through the difficult time, Maria drew strength from her family, especially her father, sister, and partner. (*Humugot ng lakas sa pamilya, lalo na sa Papa, kapatid, at asawa.*) Her friends know that she had TB and is now cured, so they refer neighbors who are experiencing the same symptoms to talk with her. She generously shares information and tips with them: "Be strong and face your problems, especially if you have young children who are dependent on you." (*Magpaka-tatag. Harapin ang problema, lalo na para sa mga anak na umaasa sa inyo.*)

Insights and Recommendations

There is a thin line between caution and discrimination. In Maria's case, she had to accept being separated from her infant and partner so that they would not be infected with TB from close contact with her. She was able to overcome her separation anxiety by focusing on the higher good of keeping her loved ones healthy. Once cured, she has tried to avoid vices and adopted healthy behaviors to ensure that she will not have a relapse. She shares her experiences to help others understand the disease and, hopefully, prevent it from spreading further.

MARICEL

Her video on YouTube® has been viewed more than 100,000 times. The comments speak of how her story has inspired viewers (*nabuhayan ng loob*) who were despondent about themselves or family members who have TB. Their burden is lifted by hearing from someone who has been through the ordeal and is now cured. And that is precisely why she is sharing her story. Maricel hopes that no other child will ever have to go through the harrowing experiences that she had because of the death of a parent from tuberculosis (TB).

Maricel's mother was a nurse in the biggest hospital in Saudi Arabia. She died from eclampsia during childbirth because she happened to go into labor during Ramadan when most of the Muslim staff were on holiday and no doctor was available. Her father brought up Maricel and four other siblings. Maricel was always "Daddy's girl" so his death from TB when she was six years old had a great impact on her. After the burial, Maricel and her siblings were distributed among different relatives: Maricel went to live with an aunt in Laguna; one sibling was sent to a relative in Bulacan; and the others stayed in Pangasinan, but with different relatives on both their mother's and father's side of the family. Later, Maricel took a two-year junior secretarial course. She stoically endured the household chores she had to do on top of the long commute to and from school in Makati City.

Upon graduation, Maricel went back to Pangasinan to take care of her grandmother until relatives took her lola to Bulacan. As the eldest child, Maricel felt obliged to help her siblings. She took on any work she could: She sold housewares, books, and many other

things from Pangasinan to La Union to Zambales, and to Manila, just so she could send her siblings a small allowance. She found work selling spa equipment which turned out to be something she did quite well. As a reward, she was given the opportunity to train as a reflexologist. Once again, she proved her mettle and was recruited to be a personal therapist. Her new employer owned a factory that made angel figures where she also worked as inventory clerk. This was where she met her husband.

Maricel and her husband started their married life in Bicol, his hometown. They made a living buying and selling copra and pili nuts that she augmented by doing massage. In 2004, Maricel had an ectopic pregnancy and the couple had to move to Pangasinan so that relatives could take care of her while her husband was away at work. Maricel delivered her first baby, a girl, in 2005. They had a son in 2007. By this time, the family had settled in Montalban, a municipality of Rizal province adjacent to Metro Manila. Maricel started working as a clerk in the local university (*Pamantasan ng Montalban*) in 2010.

In 2011, Maricel became pregnant again but lost the baby. She found out that she was diabetic during a prenatal checkup. Soon after, she developed a cough that would not stop. She consulted a private physician who prescribed antibiotics because she had been coughing for more than two weeks. Maricel bought the antibiotics but stopped taking them after three days. She was compelled to finish the antibiotics when her cough returned so she finished the seven-day course, but not according to schedule. Maricel began coughing again after one month. She consulted

a different doctor who diagnosed her with bronchopneumonia and prescribed another course of antibiotics. Still, her cough continued even after she finished taking the antibiotics so Maricel consulted another doctor. Her chest x-ray showed TB and the doctor prescribed rifampicin for six months. After two months, Maricel ran out of money to sustain her medicines. She asked one of her regular massage customers who worked in the health center to help her enroll in the TB program.

At the Health Facility

Maricel was able to complete the six-month treatment for Pulmonary TB (PTB) through her friend's help. She did her best to comply with the treatment regimen, although she admits to missing one or two doses. (*Kailangan kasi, walang laman ang tiyan bago uminom ng gamot. May isa o dalawang beses na nakakain na ako bago ko naalala.*) She also complied with having chest x-rays done six months after treatment and again after eight months. She was due for another checkup when she started coughing again. This time, the doctor referred her to a government health center where the staff referred her to a government hospital for sputum examination and x-ray. This government hospital is in an adjacent municipality, so Maricel had to take several rides to get there. After completing requirements, she was told to go back to the health center for instructions.

Back at the health center, the Barangay Health Worker (BHW) met Maricel outside the door. She was not allowed to enter the

building because she might infect the people there. (*Hindi ka puwede pumasok dito; baka mahawa mo kaming lahat.*) Maricel felt dejected. She lost all hope of getting treatment, much less of getting cured. She honestly believed that she would suffer the same fate as her father that she already planned her funeral and bought a memorial plan. A visit from her churchmates lifted her spirits. They encouraged her to seek treatment; to strive to regain her health for the sake of her young children.

Maricel went for a checkup at the Lung Center of the Philippines (LCP). Her GeneXpert examination showed her to be positive for Multi-Drug Resistant TB (MDR TB) and so she was enrolled for treatment. For the next 18 months, Maricel would travel every day from their home in Montalban to LCP with the commute taking about an hour. She would take her medicines and then vomit. She had to wait for the side effects of the medicines to subside before she could go home. There were times she could barely walk because one of the side effects of the medicines she was taking was hyperuricemia – meaning having high levels of uric acid which made her joints very painful. She also had to have injections every day for the first six months of the 18-month treatment.

Insights and Recommendations

Maricel was introduced to the concept of patient support groups in LCP. Here, former patients volunteer to counsel new patients, encouraging them to comply with treatment requirements and to endure the side effects to achieve cure. Maricel resolved to

be cured to spare her children the hardships she suffered as an orphan. She decided to volunteer in LCP when she was cured, testifying that cure is possible.

Being an active volunteer has given Maricel the opportunity to be the voice of the TB community in local and international fora. It has given her the chance to learn new skills to enhance personal and professional growth. And it has given her the courage to stand up for her rights and the rights of other TB patients. As well, she takes the chance to educate TB patients about their responsibilities to the community. Whereas the COVID-19 pandemic has put a damper on activities of the patient support group, Maricel continues to refer patients to the LCP.

MAY

Her voice quivers and her eyes tear up when asked about her experience with discrimination. That is how deeply she still feels about the incident that happened three years ago.

May is now 42 years old, married, with three children, aged 21, 18, and 14 years old. The two younger children attend local schools, while the eldest is currently unemployed. May's husband is the family's sole breadwinner, a cashier in a gasoline station.

May tried to pursue her education even when she was already married, but her oldest son was born prematurely and was quite sickly. She was unable to finish her course because of frequent absences to take care of her son. From then on, she and her husband agreed that she would focus on their children.

May's family is from Navotas City, site of the biggest fish port in Metro Manila. To contribute to the family's finances, May helped relatives sell fish in their market stall, leaving the children in the care of her mother-in-law.

In 2012, May decided to have a checkup at the health center because of a persistent cough. She was asked to leave a sputum specimen for examination. When she returned for the results, she was instructed to have a chest x-ray. The chest x-ray confirmed that she had Pulmonary TB (PTB). May says that she was not surprised to be diagnosed with PTB. Her grandfather died from pneumonia and she believed she had the familial predisposition for weak lungs (*mahina ang baga*). May was enrolled as a Category 1 TB patient at the health center. The nurse dutifully

brought her medicines and supervised her intake every day for the entire six months of her treatment, after which she was declared "cured."

In March 2017, May experienced hemoptysis, so she went for a checkup at the health center. She was referred to the Tayuman branch of the Philippine Tuberculosis Society, Inc. (PTSI) where she was eventually diagnosed with Multi-Drug Resistant TB (MDR TB). The staff carefully explained her condition. May understood MDR TB to be more serious than her previous TB disease. She understood that she needed to judiciously submit to the daily treatment regimen over the next two years to be cured and that the consequences of not adhering to the treatment protocol could mean that she would not be cured and could even cause her death. May resolved to undergo treatment and be cured for the sake of her family. Most importantly, she did not want to infect her children.

May had to commute from her residence in Navotas to the treatment center every day, taking two jeepney rides that cost 40 pesos (about US$1). She would leave home after breakfast, arriving at the clinic at around 10 a.m., where she and other MDR TB patients took their medicines and injections. The large pills were difficult to swallow, and the injections hurt, but she endured. After some time, she felt the side effects of the drugs they were taking. She carried a disposable bag in case she vomited from being dizzy and nauseous. The retching would leave her extremely debilitated. Once the ill feeling passed (*nahimasmasan*), she would go over to a nearby eatery

(*carinderia*) to eat before heading home at around 4 p.m. She wore sunglasses because the TB medicines rendered her sensitive to light. Being with the other TB patients every day, experiencing the side effects of the TB medicines together, forged a bond between them. Eventually, May joined a support group formed under the direction of their health worker.

At the Health Facility

After three months of treatment and two subsequent negative cultures, the PTSI Tayuman staff informed May that she would be "decentralized," meaning that she would be endorsed to a health facility closer to her residence to spare her the long daily commute to the clinic. The nurse from PTSI Tayuman accompanied her to the health center whose staff would now be responsible for supervising her treatment and monitoring her case.

The Barangay Health Worker (BHW) took her to the back of the health center, outside the building, to be sure that she would not infect the other clients and staff of the health center. May knew that her TB was controlled and she was no longer infectious, so she thought that she did not need to be separated from the other clients. She kept her thoughts to herself and complied. May was instructed to come for treatment at 4 p.m., just around closing time of the health center, so that there would be less chances of interaction with other clients. The BHW would put her medicines on a chair outside the back of the building and hurry back inside. May had to call out to the staff when she finished taking her medicines.

This was quite a change from the process in her previous facility where the nurse supervised and encouraged patients as they took their medicines. May also missed the supportive presence of the other patients who had become her friends. And because she took the medicines late in the afternoon, May had to endure the side effects late into the night, depriving her of much-needed sleep. (*Masama ang pakiramdam ko magdamag. Mga 2 a.m. na ako nakakatulog.*) After a week, May decided she had enough and went back to PTSI Tayuman where she eventually completed treatment in 2019.

In the Community

When May was just starting treatment, the nurse visited her at home. In a small community like theirs, this attracted quite a lot of attention. Specifically, her neighbors were curious as to why the nurse was wearing a mask. As a result, neighbors who used to frequent her house stopped visiting altogether, fearing they could get infected. May was offended, but she tried to understand them. (*Ang importante, naggagamot ka at alam mong hindi ka nakakahawa.*) May has gained so much knowledge from her experiences that now, neighbors seek her out when they need information about their health.

One day, one of the patients invited her peers to celebrate her birthday. At the party, May and her friends noticed that the other guests, cousins of the birthday celebrator, whispered surreptitiously among themselves. They also tried very hard to avoid May and her friends who found the situation ridiculous,

considering that the birthday celebrator was also undergoing treatment, just like them. They opted to ignore the slight and just enjoy the celebration.

Insights and Recommendations

These experiences underscore the importance of education and the provision of accurate information, first to health workers (*Sila mismo hindi nakaka-intindi na hindi kami dapat ihiwalay*) and then to the general public (*Natatakot silang mahawa, maski hindi na kami nakakahawa.*) May understands that there is still a long way to go, that is why she decided to lend her voice to this advocacy to eliminate stigma and discrimination.

Through all the difficulties and heartaches, May is grateful for the unwavering support of her family, especially her late mother-in-law who took care of her children in her absence. May also received support from the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM) so she did not have to pay for treatment. In addition, she received an allowance to cover expenses for transportation and food while under treatment. Whenever she is tempted to complain, her husband reminds her to be grateful instead.

MHAE

Mhae was adopted by her father's sister as a child, but she ended up earning a living for her birth family. When she was 13 years old in third year high school, she began working in a small factory that manufactured light bulbs, just across from where she lived. She would work from 8 a.m. to 12 p.m.; run home to change into her school uniform; and attend classes from 1 p.m. to 6 p.m. Understandably, she did not perform well in school. Her relatives urged her to stop wasting her time in school and just work. She faked her age in her biodata sheet, saying that she was 18 years old so she could be employed. Her lack of experience and education meant that she had to settle for whatever work she could get, hopping from one job to another (*palipat-lipat*).

As a 19-year-old worker in a paper factory she became involved with her supervisor who was 13 years her senior. He introduced himself as a single man and asked Mhae to live with him. Soon Mhae found out that he was using drugs and alcohol. He began hitting Mhae. (*Nananakit.*) Mhae learned that he had two other partners, and that he had two sons with one partner and three sons with the other partner in addition to the daughter he and Mhae had together. She tried to end the relationship, but he was adamant about staying together because he adored his daughter. Until one of the women he was involved with attacked them in a scene straight out of a television drama, creating chaos in the community. Mhae picked up her daughter and ran away, leaving everything behind. She soon left her daughter with an aunt; moved to another city; and started working in a bar.

Not long after, Mhae met a childhood friend and they soon moved in together. Her next baby was born prematurely

because Mhae was coughing incessantly throughout her pregnancy. One time, she coughed so hard that she pushed the baby out. (*Naiire.*) Her partner's mother brought the baby home because Mhae remained in the hospital for treatment of pneumonia and tuberculosis (TB).

Upon discharge, Mhae found work as a masseuse in a spa, but she started coughing and having fever again. The barangay health center referred her to the Lung Center of the Philippines (LCP) where she was diagnosed with Multi-Drug Resistant TB (MDR TB). She started treatment in 2017 and completed this in 2019. The health workers in LCP warned her that she had extensive damage in her lungs and told her to be very careful so that she would not be sick again.

Mhae became pregnant with her third child at the height of the COVID-19 pandemic. She was unable to go for prenatal checkups because of the lockdown. She delivered a healthy baby boy at home with the help of a midwife. The baby is now almost two years old, but the birth has not been registered; neither has the baby received the requisite childhood immunizations.

The COVID-19 pandemic made blended learning the norm, forcing parents to take on more responsibility for teaching their children. Mhae became exceedingly stressed supervising her daughter's completion of school modules. She wants her daughter to be able to keep her scholarship. Mhae began experiencing flu-like symptoms again and spitting blood-stained phlegm. She was admitted at the LCP twice during the last quarter of 2021. At the

time of the interview for this story, she had just undergone a CT scan with contrast. She was referred to the East Avenue Medical Center for edema (*lumalaki ang tiyan*) and because one of her arms was visibly bigger than the other.

In the Community

Naturally gregarious and outgoing, Mhae had many friends in the community. They used to visit each other and have drinks together. She chose one of them to be her son's baptismal godmother. This "co-parent" (*kumare*) allowed Mhae's family to tap into their electrical connection. When Mhae was cash-strapped because of her illness and unable to give her share for the electric bill, her kumare cut off the connection. Moreover, the kumare became angry when she found out that another neighbor allowed Mhae to tap into their connection. She accosted Mhae for playing music too loud. She subjected Mhae to a verbal tirade about her illness that could be heard by the entire community. (*Maganda ka nga, may TB naman.*) Mhae reported the incident to the people at her treatment center who advised her to file charges with the barangay. However, Mhae chose to keep the peace and avoid further altercations by remaining indoors, away from vicious gossip and hurtful comments. Her erstwhile friend is no ordinary friend. She is her *kumare* after all, one who stood as sponsor during her son's baptism and as co-parent with Mhae.

Insights and Recommendations

This story emphasizes the need for public education on TB. As well, it surfaces the need for structures to support TB patients in

the community. Mhae tried to safeguard her security and dignity by reporting the incident to her treatment program, her act signifying a plea for help. She was told to lodge a complaint with the barangay, which is the procedure followed in the community. Mhae chose to suffer in silence. Alternatively, a support group of patients in the barangay could initiate action with the head of the health committee of the Barangay Development Council to reconcile the feuding parties and hold educational sessions in the community.

NHELS

In 2019, Nhels was at the top of his game, earning a substantial income as a credit card agent. He worked hard and played even harder, burning the candle at both ends. He admits the disposable income facilitated the fast life he lived: alcohol, late-night parties, fun times (*Naabuso ang sarili. Puyat, gala, lahat ng saya sa buhay, nasubukan ko.*) Until he began experiencing symptoms that rang alarm bells. He began to feel chilly, even if the office temperature never bothered him before. When he started having back pains, he asked to be moved to a different workstation away from the direction of the draft of the air conditioning, but the chills persisted. Coworkers commented on his obvious weight loss, even if he had not been deliberately trying to lose weight. He lost his usual appetite, and he was always tired. He would be shivering and feverish on the commute home. He took over-the-counter medicines to ease the flu-like symptoms. His sister observed all these and insisted on consulting in a private clinic. Nhels opted for a thorough checkup with blood work and chest x-ray. The results showed that he had tuberculosis (TB). The private doctor advised him to go to the government health center for treatment. The nurse at the health center was kind and accommodating. She told Nhels that he had a different kind of TB that could be better managed at the Lung Center of the Philippines (LCP).

Nhels was despondent, he thought it might be better to end it all. He obtained a length of rope, ready to hang himself.

What he saw at the LCP turned him around. There were patients who were in a far worse condition than he was in and they were

fighting to gain back their health. He saw patients who were so weak that they had to be in wheelchairs. He recalls seeing somebody with a tube sticking out of his side. Nhels thought: "If these patients can still put up a fight, so can I." (*Kung sila nga na mas malala ang condition kinakaya magpagamot, mas kaya ko.*) He resolved to keep fighting until he was cured.

Nhels started treatment in January 2020. He endured taking as many as 28 pills and one injection every day for the first three months. Sometimes, he was just so tired of having to take all the pills that he would start vomiting as soon as the nurse handed him his medicines for the day, even before he took one of them. He is grateful for the support of all the health workers and his fellow patients who never failed to encourage him, particularly when he was feeling low. When he vomited, they would instruct him to check if he vomited any of the medicines, and, if he did, to ask the nurse to replace these and take it again. They were generous in sharing their own experiences to help him cope with the treatment. They taught him to take the medicines in a slow, steady manner to minimize the gagging. It usually took him around an hour to swallow all the pills. To make matters worse, his treatment coincided with the imposition of the lockdown when COVID-19 broke out. LCP transferred responsibility for his treatment to a satellite clinic near his residence and shifted to online monitoring. This meant that Nhels had to make a video call to the health center everyday so that the nurse could observe him taking his medicines. To minimize his going out of the house, he was given one month's supply of medicines.

Nhels was inspired to continue treatment when he began to feel better after the third month of treatment. His appetite returned, he enjoyed eating again, and he gained weight. His patience, persistence, and compliance paid off. In November 2020, he was certified "cured" after 11 months of treatment. Nhels now practices a healthy lifestyle. He is usually asleep by 10 p.m.; wakes up early; tries to take a walk before breakfast; and sticks to a healthy diet with the help of his sister. He works as staff of one of the councilors in his local government unit (LGU). Nhels is profusely grateful to the Rodriguez rural health unit (RHU) and its health workers, particularly Dr. Hazel Montolo and Nurse Jane Tolentino for having been with him on his journey back to wellness. (*Hindi po nila ako pinabayaan kaya hindi ko sila malilimutan.*)

Self-Discrimination

When Nhels was diagnosed with Multi-Drug Resistant TB (MDR TB), he decided to move out of the house he shares with his sister's family for fear of infecting his young nephews and nieces. He also did not want to see his sister crying when she saw him struggling with his medicines. His sister has been his strongest supporter and ally in his fight against TB. Nhels rented a room in the same compound so he could have his own space. His sister cooks all his meals for him.

In the Community

The community where Nhels lives has an active Homeowners' Association (HOA). Someone shared screenshots of what was

supposed to be a secret "chat" among some members. One person in the chat group disparaged Nhels and dissuaded the others from including him in their activities because he had TB and they might get infected. (*Huwag na natin isama yan. May sakit na TB yan, baka mahawa tayo.*) Nhels confronted the gossipmonger and told her off. He explained that TB is indeed a communicable disease, but that it can be treated and cured. Moreover, once a patient test negative, the illness is no longer infectious. Nhels told her that engaging in character defamation is a crime with civil liabilities. He fully intended to file an official complaint with the barangay, but the sister of the gossipmonger died and so Nhels desisted out of humanitarian consideration. After the funeral, the person apologized to Nhels which he graciously accepted.

Insights and Recommendations

Nhels urges anyone who is experiencing symptoms to consult a doctor as soon as possible so that they can be treated immediately and can prevent spreading the infection to others, especially their loved ones. Medicines, services, and laboratory examinations are all provided for free, but it is the patients' responsibility to comply with the treatment. Failure to do so could mean extending the length of treatment; unsuccessful treatment; and the patient getting a more severe form of disease and possibly, dying from TB. Out of gratitude, Nhels now volunteers to help patients who are undergoing treatment. The nurse at the health center relies on him and other cured patients to trace patients who fail to report for treatment and to

encourage them to continue. (*Tumitigil pag nakaramdam na ng ginahawa.*)

Nhel's story teaches that patients should not be cowed when they experience discrimination because bullies thrive when no one stands up to them. Rather, patients should take every opportunity to educate others on the basic facts about TB: (1) Anyone can get it; (2) TB can be cured; (3) A patient is no longer infectious after two to three weeks of treatment; (4) We can all do our part to stop TB from spreading.

PAKS

Paks was a child when his father left to work abroad. They never heard from him again. Paks spent his younger years shuttling between Manila and Pangasinan, a province north of the metropolis, depending on where his basic needs for food, shelter, and education could be met. Paks is a nickname; a shortened form of the word *pasiking*, the Pangasinan term for "nitpicky" or *makulit* in Tagalog.

After completing his primary education in Manila, Paks lived with an aunt in the province. He struggled to finish high school. He had to lead the livestock to pasture before school and herd them home after school. He was frequently absent because he was expected to help plant rice during the rainy season and corn during the dry season. He helped carry the seedlings and plant them in the paddies. He learned to operate farm machinery and to manage the irrigation system that brought water to the different areas in the farm, carrying and connecting the heavy hoses. During harvest, he helped reap the grain (*naggagapas*), thresh them to separate the grain from the stalks, lay out the unhusked rice (*palay*) or corn to dry, and gather and carry heavy sacks of grain for storage. Because of poverty, Paks performed hard labor with inadequate nutrition, leaving him susceptible to infection.

In the interim period between high school and college, he vomited blood. His mother brought him to Manila for treatment of Drug-Susceptible TB (DSTB) at the Tayuman clinic of the Philippine Tuberculosis Society, Inc. (PTSI). After completing the six-month treatment, he began working odd jobs at the

recommendation of family and friends. He started out as a barista/cook in a coffee shop, but he contracted influenza. He decided not to return to work. Then he worked as maintenance crew of a water refilling station but living in the workplace meant he was on call 24/7, and he had to lift the containers of water. It was too taxing for him, so he stopped working there and took a rest. By this time, his mother had put up a small computer rental shop south of Manila and asked him to manage it. He began vomiting blood again, which he tried to keep from his mother for as long as he could.

When he could no longer keep his illness (*lumala na*) from his mother, she took him back to PTSI Tayuman. The staff explained that the TB he had was not the kind that could be treated in six months. This time, he had Multi-Drug Resistant (MDR TB) and the treatment would take 18 to 24 months. He would need to take medicines and have injections every day for the first six months and continue taking the medicines until he was cured. He started treatment in 2015 and completed the course in 2017.

Certified "cured," Paks was invited to join Samahan ng Lusog Baga Association, Inc. (SLBAI), a peer support group formed by the Department of Health National TB Control Program (DOH-NTP). Patients who have completed treatment encourage new MDR TB patients to stay in the program and achieve cure. Three months after he started volunteering in SLBAI, Paks met a new patient, Jeannie. Paks was attracted to Jeannie because of her sweet and loving nature. She was especially thoughtful of her family. Soon, they were spending time together every day after

treatment. They bonded over their common experiences as MDR TB patients. Like any couple, they shared simple dreams, especially one of owning a home and starting a family. Soon, Jeannie became pregnant. She continued and completed treatment. Her family lived north of Manila, so she went for prenatal consultations in a government hospital close to their residence. Paks was managing his mother's computer shop south of the metro. Jeannie stayed with Paks and his family for a time but went back to her family's home to be closer to the hospital as her due date approached. Paks reminded Jeannie to disclose her status as MDR TB-positive to her obstetrician-gynecologist.

At the Hospital

On September 22, 2017, Jeannie was given medicine to induce labor. The next day, her water broke. Paks and Jeannie's mother brought her to the hospital. Her mother disclosed Jeannie's MDR TB status to the obstetrician-gynecologist on duty who asked them to transfer Jeannie to San Lazaro Hospital in Manila. According to the doctor, it was not in her prenatal records that she was MDR TB-positive, and that the local hospital did not have the capability to handle child delivery by mothers with MDR TB. The doctor averred that San Lazaro Hospital — being the foremost infectious disease hospital in the country — had the facilities to attend to MDR TB patients. Jeannie's mother tried to explain that she had completed treatment and was no longer infectious. Paks implored the doctor to deliver the baby as birth seemed imminent, but his pleas fell on deaf ears. To

top it all, there was no ambulance available, and it took a while to convince a taxi driver to take Jeannie to San Lazaro Hospital.

The distraught couple reached San Lazaro Hospital in the wee hours of September 24, 2017 where they were attended to expeditiously. Jeannie was weak and had difficulty breathing, and after a while the doctors asked Paks to give his permission to deliver by caesarian section. Paks had to buy all the supplies needed for caesarian delivery. The baby was separated from Jeannie immediately after delivery and placed in a pediatric ward; not in the nursery. The baby was treated right away because he was vomiting phlegm. Jeannie's mother was able to bring the baby home upon discharge on September 26, 2017.

Paks stayed behind to take care of Jeannie who was still having difficulty breathing. He kept going to the nurses' station to ask for help, even begging for a different doctor. The nurses kept assuring him that they had already raised his concerns to their supervisors and that these would be attended to. But no help came.

Later that evening, Jeannie's sister and sister-in-law came to take over watcher duty. They convinced Paks to go home and get some sleep as he had not had any rest for three nights. He agreed to go home to rest, check on the baby, and get a pillow that Jeannie was asking for. He returned early the next morning only to be told that Jeannie had expired. He had no time to take it all in, much less, grieve. He had to work on all the required documents so that they could bring Jeannie home.

Maricel Buen was president of SLBAI at that time. She received a call from Paks and Jeannie when they were asked to transfer to San Lazaro Hospital. Some members of the group even visited them, so they were upset at Jeannie's untimely demise. After Jeannie's funeral, they vowed to support Paks if he wanted to file a case against the hospital and doctor who turned them away. But Paks felt that he had no fight left in him. He lacked the energy for anything more than mustering his strength so he could focus on taking care of his son. Besides, nothing could bring back his Jeannie. (*Ipinasa Diyos ko na lang po. Hindi na po mabubuhay ulit si Jeannie maski magreklamo ako.*)

SLBAI drafted a formal complaint under the direction of their adviser and with the help of their consultant. DOH organized a meeting. Present were representatives of the National TB Control Program (NTP), representatives of the hospital, officers of SLBAI, and Jeannie's mother. In the end, Jeannie's mother opted to settle amicably and not pursue the complaint.

Insights and Recommendations

SLBAI showed solidarity in their ranks when they took up the cudgels for Paks and Jeannie. The group may need to initiate more regular and more intensive discussions about patient's rights and responsibilities because patients often do not realize when their rights are already being violated. At the same time, patients need to understand that rights come with responsibilities.

The Patients' Charter states that patients have the right to respect and dignity:

The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities. The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community.

Should their rights be violated, patients have the right to seek justice:

The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly.

To foster patients' rights, there should be a clear process for any infractions. There should be a "duty officer" to whom issues can be raised, and who can make corrective actions when infractions occur. Information about the process for making complaints and about the person to whom patients can report violations of their rights should be displayed prominently in the hospital or health facility.

At the same time, patients have "the responsibility to provide the healthcare giver as much information as possible about present health, past illnesses, any allergies, and any other relevant details." As well, patients must be considerate of the

rights of other patients and health workers, meaning that they should adopt measures to protect others from infection.

Efforts to develop a heart for service and respect for the rights of patients should be part of all training for health workers and support staff, including cleaners and security guards.

PAULINE

Pauline leaves the house at daybreak to buy ingredients for the snacks she cooks and sells outside her home in a crowded urban community. Back at home, she sets up the table and begins preparing barbecue, fish balls, and other snacks, along with cold drinks (*sa malamig*). She keeps her stall open late into the night to supplement her partner's earnings as inventory staff in an aluminum factory. They need to support their blended family: Pauline has four children from a previous relationship and two with her current partner.

Pauline was 15 years old and in second year high school when she became pregnant. She stopped schooling and moved into her boyfriend's home. She gave birth when she was 16 years old, but her baby had to be placed in the neonatal intensive care unit (NICU) because of respiratory problems. The baby lived for five months. Then her boyfriend was incarcerated on drug charges, and she lost contact with him.

Her second partner was a drug-dependent who beat her up when he could not have drugs. Pauline charged him with violence against women (VAW), which landed him in jail. Next, Pauline tried her luck as a domestic helper in Singapore, but her employer lost his job after six months, so she had to come back to the Philippines. She found out that her former partner – the one who beat her up – was free, and that there was no record of the VAW charges she had filed against him. He continues to disturb Pauline: He has threatened to burn down her house, has overturned the table of snacks she is selling and damaged the side mirror of a friend's motorcycle.

Pauline learned that she was in the local government's drug list, so she opted to surrender to the Barangay Anti-Drug Abuse Council (BADAC). She participated in recreational activities like Zumba and income generating projects. This was where she met her current partner with whom she now has two sons. The youngest boy is under two years of age, conceived and born during the COVID-19 pandemic. Pauline was unable to access prenatal care and delivered at home with the help of a midwife. The birth has not been registered and the baby did not undergo newborn screening; neither does he have any of the required immunizations.

In 2015, Pauline experienced rapid weight loss and difficulty in breathing. To be able to sleep, she needed to pile up pillows so she could recline in an almost uprights position. Her x-ray showed that she had Pulmonary TB (PTB) and fluid in her lungs. She resolved to follow all the doctor's instructions and take all her medicines so that she would get well for the sake of her children. She was cleared after nine months. The health care worker explained that she would always have the scars on her lungs. She was declared "fit to work" in 2017.

At the Health Facility

Pauline first consulted a private physician, but the cost was prohibitive, so she transferred to a barangay health center. She had to queue for hours to avail of services. To be among the first in line, she tried to be at the health center before it opened at 8 a.m. It would be around noon before she could go home.

There were also times when there was no doctor, resulting in intermittent treatment.

At Home

At home, Pauline immediately separated her eating utensils from those for the rest of the household.

In the Community

Pauline is sociable, often hosting impromptu gatherings of friends and neighbors. She confesses to indulging in alcoholic beverages, smoking cigarettes, and gambling. (*Inabuso ang katawan sa alak, sugal, at sigarilyo.*) Neighbors saw a nurse wearing a mask visit Pauline at home. This was pre-pandemic, when it was unusual for people to be wearing masks so the neighbors concluded that Pauline must have an infectious illness. Friends stopped dropping by to see her. She felt like she was drowning – not from the fluid in her lungs – but from the isolation. After being declared "cured" in 2019, she attended the birthday celebration of one of her friends. It was like announcing her return to social life in the community. Her friends started getting together with her again to bond over liquor (*tagay*) and cigarettes.

Insights and Recommendations

Pauline advises her friends to take care of their health for the sake of their children. (*Huwag abusuhin ang katawan dahil*

kailangan ng mga anak.) She also tells them to get checked right away if they feel sick so that they can be treated for whatever is ailing them.

SANDY

As a fresh accounting graduate in 2007, Sandy was eager to find a job and start earning to give back to her family. The human resource office of a well-known retail chain already short-listed Sandy for employment and she just had to go through the medical examination to be certified by the company physician as "fit to work." Unfortunately, her chest x-ray revealed that she had tuberculosis (TB). She consulted a private physician who prescribed medicines. She bought the medicines and took them for six months, enduring the itchy rashes that develop as a side effect.

Sandy completed treatment and landed a job as accounting staff in a leading educational institution in engineering and information technology in 2008. In 2014, she developed a non-stop cough, prompting her to consult at the Lung Center of the Philippines (LCP). She was given the same medicines she took the first time she was diagnosed with TB. She returned to the clinic after one month because she did not feel any improvement in her condition. She was referred to the Programmatic Management of Drug-Resistant TB (PMDT). Sandy's GeneXpert test showed her TB to be resistant to rifampicin. She was enrolled into the program, giving her free access to checkups and medicines. The school where she worked allows employees to take a sick leave for the 18-month duration of the treatment for Multi-Drug Resistant TB (MDR TB).

While on treatment, Sandy reported to LCP daily from Monday to Saturday. She would commute from the community where she lived to the LCP, arriving at around 9 a.m. The health care

workers (HCW) would give her the medicines for the day. She needed to take 15 to 18 tablets every day in addition to an injection for the first six months of treatment. She would sit at a table with other patients under the watchful eye of the HCW and start taking her medicines. She needed to pace swallowing the pills as they were quite large and difficult to swallow. The HCW would sign her booklet after she swallowed all the pills. Then Sandy would wait for the dreaded side effects and start vomiting into a plastic bag she always carried with her. Retching sapped her strength, but it gave her much-needed relief. (*Magaan ang pakiramdam.*) Then she would eat and rest for a while before going home.

At the entrance to the community where she lives, there are many street food stalls patronized by the residents. Sandy's favorite stall (*suki*) sold fried vegetable spring rolls (*lumpiang toge*). It is a tasty snack made of bean sprouts and tofu, so it is also healthy. Little did Sandy expect that this seemingly simple indulgence would lead to another health concern. She noticed that her urine became a bright red orange – an occurrence that could not be attributed to the anti-TB medicines she was taking because she was not taking rifampicin. Everything she ate made her vomit, she could not keep any food down, and she rapidly lost weight. Severely debilitated, Sandy asked her sister to bring her to the emergency room (ER) of a private hospital. The doctor and nurse on duty were solicitous. They requested laboratory tests and the medical technologist extracted blood specimens. They requested laboratory tests and the medical technologist extracted blood specimens. The

HCWs took Sandy's medical history. She disclosed that she was undergoing treatment for MDR TB, but that she was already negative. Sandy sensed an immediate change in the way the HCWs interacted with her. They hurriedly moved Sandy from the ER to an isolation ward and kept their distance from her. The doctor prescribed paracetamol for fever and pain, and the ER trip ended with Sandy and her sister deciding to go home without any further treatment. After two days and no improvement in her condition, Sandy consulted in a private clinic and diagnostic laboratory. She was diagnosed with Hepatitis A which she traced to regular consumption of street food.

Insights and Recommendations

Sandy's experience at the ER emphasizes the need to train HCWs on how to provide better care for patients – not just patients with MDR TB, but all patients – that is, with compassion even as they ensure their own protection from any possible infection.

Further, during one of Sandy's follow up checkups in LCP, the health care worker took note of her address and remarked that there were many MDR TB patients from that community. In fact, there were two recent deaths of patients from the area. It turns out that the community is located next to the city jail and exhaust fans of the jail release stale air in their direction.

Sandy hopes that telling her story will prompt health authorities to investigate cases of MDR TB in the city jail and the nearby

community, and to undertake measures to protect the health of residents as well as inmates.

SDM

SDM and his partner had been together for 18 years, and together they had four children. His world crumbled when she decided to part ways with him just when he received the results of his examination that revealed he had Muti-Drug Resistant TB (MDR TB). Instead of the care and support he so badly needed at that time, he had to deal with rejection and loss. He would have completely given up if not for his parents and siblings who rallied to his side.

SDM was a construction worker in Japan for four years, from 2004 to 2008. He was strong and able-bodied and earning quite well when he suddenly experienced symptoms that he recognized as signs of TB-rapid weight loss, coughing, and fever. (*Bumagsak ang katawan. Inubo. Nilagnat.*) He left his job and hurried home for treatment. His mother brought him to her cousin's husband, a private physician. His uncle supervised his treatment for two years until his x-ray came out clear in 2010 and he was declared "cured." However, after two months, he vomited blood and was confined for two weeks at the East Avenue Medical Center. After completing documentary requirements for his local government unit's (LGU) social services office and other laboratory examinations, he was transferred to the Lung Center of the Philippines (LCP) for treatment of MDR TB. He was asked to convince those who were living with him to also undergo screening for MDR TB. Fortunately, his parents were not infected. For everyone's safety, the family agreed to let SDM occupy a separate unit in the compound owned by his mother's family. SDM did not

feel discriminated against; in fact, he felt he was protecting his parents from infection. His parents provided everything SDM needed through the duration of treatment.

The LCP staff explained that compared to ordinary TB, MDR TB was more difficult to treat precisely because the bacteria in his body were no longer responding to the drugs that SDM had been taking. They explained that SDM had to subscribe to the treatment protocol for about 18 to 25 months or he could develop an even worse kind of TB and even die from the disease. SDM had to take 15 tablets and have an injection every day for the first six months of treatment and had to continue taking the pills until he was cured. The medicines were strong antibiotics, so some adverse reactions (ADR) were expected. SDM was encouraged as he did not experience any of these side effects on the first three months of treatment. But these hit him like a sledgehammer after the third month: dizziness, nausea, vomiting, weakness. Fortunately, support treatment and medicines were provided; for example, for diarrhea. Patients also received a transportation allowance from the Philippine Business for Social Progress (PBSP) to encourage them not to default on treatment. Patients had x-ray, sputum, and blood examinations every two months while under treatment until they were cured. SDM started treatment in 2010 and was declared "cured" in 2012.

Upon "graduation" from treatment, SDM was invited to join the Samahan ng Lusog Baga Association, Inc. (SLBAI). SLBAI

is a patient support group organized by the National TB Control Program (NTP) of the DOH. It was registered with the Securities and Exchange Commission (SEC) in 2005. SLBAI formally recognizes cured TB patients and engages them in the fight against TB. SLBAI members are invited to various forums to contribute to program planning, policymaking, and decision-making. SDM was heartened by his involvement in SLBAI. He is grateful for the opportunity to speak for people affected by TB. It gave him a change to see other places in the Philippines and to help disseminate correct information about TB through the conduct of TB 101 sessions. Most of all, he uses his own experience with MDR TB to urge patients to persist in their treatment to achieve cure and return to normal life. Many patients discontinue treatment when they feel well. (*Maraming hindi nagpapatuloy. Basta makaramdam ng ginhawa, tumitigil na.*) SDM was also tapped to be a core group leader of Breathe Free PH Community Advocates Against TB (BFPH), a group of cured TB patients organized to support patients who are undergoing treatment. Unfortunately, the group is unable to pursue activities because of the constraints brought about by the (COVID-19) pandemic.

Insights and Recommendations

SDM's experience of being rejected by his partner is like that of other patients who have been turned away by their families. No one wants to be sick, and patients need support, not rejection. There is need for a widespread information and

education campaign about TB and how families can support family members who are sick.

Peer support groups are important. Participation in activities help cured TB patients regain confidence in themselves while encouraging those who are undergoing treatment to persist in their efforts.

SYNTHESIS

This monograph documents the discrimination experiences of 15 tuberculosis (TB) patients, the lessons and insights they gained from such experiences as well as their recommendations for ending discrimination.

Of the 15 key informants (KIs), eight were female, two were male, four were gay, and one was transgender. Their ages ranged from 26 years old to 53 years old, with a median of 29 years old and mean of 36.8 years old. Six KIs were in consensual unions, five were single, three were married, and one was a widow whose husband died in a motorcycle accident.

Four KIs completed college, earning bachelor's degree in education, nursing, accountancy, and information technology. Four KIs were unable to complete courses in education and information technology. Three KIs completed vocational courses in electronics and junior secretarial. Moreover, there were four KIs who were able to earn additional credentials, such as a professional license as a registered nurse (RN), a teaching certificate, a national certificate 2 (NC2), meaning qualified to work abroad. Other skills learned as part of non-government organizations' (NGO) efforts to enhance the income-generating capacity of TB patients were bookkeeping and reflexology. Three of the KIs are now employed by their respective local government units (LGUs) as HIV counselor, barangay clerk, and staff of a councilor. Others have found work with NGOs and the

local office of a national government agency (NGA). One works as staff in a private office while one manages a computer shop and another tends a sari-sari store. Those who "just" stay at home try to contribute to the family's income by selling snacks and other goods, accepting "piece work" that they can do at home, and online tutoring.

Regarding co-infections, five of the KIs are also living with HIV, while one has diabetes, and another contracted hepatitis which she attributes to frequent snacking on street foods. Six KIs had a family member who also had TB. Two KIs had grandfathers and a father who succumbed to the disease. One KI's mother was cured of TB, but later died from kidney failure, a complication of her treatment, and another KI's mother died from TB. Others had aunts and uncles who died from TB; one has a brother who was cured of pediatric TB; and one has a brother who is undergoing treatment for TB.

EXPERIENCE OF DISCRIMINATION

Self-discrimination/isolation

Upon learning that they have TB, it is common practice for KIs to separate their eating utensils from those of the rest of the household, even if health care workers (HCWs) try to explain that TB is spread through the inhalation of aerosolized droplets and not through eating utensils. They go through great effort to minimize contact with family members so as not to infect them, like confining themselves to their own room, only going out

to eat when the rest of the family are done eating. Some even go to the extent of renting a separate room to live in, although remaining near the family dwelling place.

Family members and/or close persons

As one KI rued, "Those who are close to you are the ones who don't understand." (*Kung sino pa ang malapit sa iyo, sila pa ang hindi nakakaintindi.*) Several KIs were confronted by relatives after they saw their story featured on television. The relatives (brother, cousin, ex-boyfriend) accused the KIs of bringing shame to the family and said they did not want to be associated with the TB patient. According to one KI, the mother of her partner took her baby so she would not infect her. One KI says that his wife left him for another man when he found out he had TB.

Community and workplace

At least six KIs experienced discrimination in the community and workplace. Discriminatory behavior included gossip about the health status of the KI and other disparaging remarks. One KI experienced being berated in public by a former friend and having the power connection to her house cut. Another KI was the subject of malicious "chat" on social media where the chat participants were enjoined not to include him in activities of the homeowner's association because he had TB and might infect them. Lastly, another KI was deliberately excluded by co-workers from joining them for lunch when she was diagnosed with TB.

Work

Most KIs have difficulty finding work and staying on the job. It could be because of the general lack of opportunities for employment, especially with the COVID-19 pandemic, or their qualifications do not match job market requirements, not necessarily because of their having TB. Moreover, employers require a medical examination and if the applicants' chest x-ray shows scars from TB, they are no longer considered for employment. Sometimes, even when a KI is employed, the working conditions can be detrimental to the KI's health. For example, a cured TB patient was accepted for work in a call center. Aware that he needs ample rest, he asked not to be assigned to the night shift and the HR officer agreed. However, he was immediately given night duty on his first day at work and he felt he could not object.

To be fair, there are employers who offer to reinstate KIs when they can go back to work again. Government agencies allow employees to go on extended sick leave if they have TB.

Health protocols

Health systems and procedures are crafted to facilitate implementation by health care workers (HCWs) who carry out the programs, often without the inputs of the patients who go through the procedures. One KI had to undergo several courses of treatment for TB without success, until she tested positive for HIV and her TB medications were adjusted accordingly. A KI was

asked to restart treatment when she tried to transfer to a public facility after initiating treatment with a private physician. Another KI had to commute from one health facility to another to access the diagnostic services that she needed. When she finally had her test results, she was told to go to still another facility. She felt so frustrated that she decided not to seek treatment anymore. Two KIs who were "decentralized" – meaning their treatment was transferred to health facilities closer to their residences – were stupefied with the rude treatment that they got in the new facilities. They opted to return to their original facilities, even if it meant a longer commute and more transportation expenses. In one facility, the HCW avoided any interaction with the patient, leaving medicines on a chair at the back of the facility and retrieving the chair after the patient took her medicines. Medicines were also given late in the afternoon, after all other patients had been served, resulting in great inconvenience to the TB patient.

Harsh treatment by health care workers

One impediment to health-seeking behavior is the unkind and unfriendly treatment patients get from HCWs in health facilities. Several KIs were not allowed into the building to prevent infecting other clients, especially pregnant women and young children. Worse, they were admonished by the HCW on duty in front of other clients. Some facilities designate an area for TB patients but his practice fosters discrimination – when people see patients in that area, they automatically conclude the patient has TB and must be avoided. Some HCWs have no regard for

patients' dignity, with one going to the extent of administering injections on the buttocks where people could see the procedure being done. One KI's request for laboratory examinations was not attended to because he was not a paying client. Two KIs were disallowed from being admitted as childbirth patients at a hospital accessible to them because the hospital staff claimed they were not equipped to handle deliveries by patients with infectious diseases like TB. It did not matter that the KIs tried to explain that they were no longer infectious.

It is worth noting that not all health facilities have HCWs from hell. One KI was pleasantly surprised with the patient-friendly service that she received when she had to transfer to another facility temporarily. She had already grown accustomed to the grudging, even grumpy, treatment in her home facility. (Mayroon naman palang ganito. Sana all.) KIs profusely than the health care workers at the LCP, PTSI Tayuman, and Rodriguez RHU for helping them recover from TB.

Reproductive health concerns

Some patients reported increased libido which clinicians attribute to enhanced feelings of wellness as the treatment takes effect. TB patients are strongly advised no to get pregnant while on treatment but are not given contraceptive options. One of the KIs was diagnosed with TB when she went for her first prenatal checkup while another one got pregnant while on treatment.

RECOMMENDATIONS

"Nothing about us without us" is the clarion call to action of the Philippine Alliance to Stop TB (PASTB). They are pushing for changes to RA 10767: *An Act Establishing a Comprehensive Philippine Plan of Action to Eliminate TB as a Public Health Problem and Appropriating Funds Therefore (2016)* – to ensure that the law reflects the voices of those most affected by TB and embodies their hopes and aspirations. The proposed amendments to the law include measures to eliminate TB-related discrimination.

Education

Education is the most potent weapon against discrimination. Educational efforts need to address patients, the public, and HCWs.

- Patients must know and understand their rights so they can claim what is rightfully theirs. The stories related by the KIs reveal that patients are often unaware that their rights are already being trampled. Patients' rights include the right to care, dignity, information, choice, confidentiality, justice, organization, and security.

- At the same time, patients need to appreciate that rights come with responsibilities. Patients must provide all the necessary and correct information that could affect their

treatment, and they must comply with treatment. To the best of their ability, they must make sure that they do not spread the infection to others, and they should be supportive of fellow TB patients. These are detailed in the Patients' Charter and mirrored and amplified in Section 15 of RA 10767.

• Efforts to foster better public understanding of TB as a disease must highlight the need for compassion and emphasize correct information to dispel fears about infection. This can work to combat discrimination against TB patients. Further, the important role of the public in preventing the spread of the disease needs to be underscored: no spitting just anywhere, covering nose and mouth when coughing or sneezing, and seeking medical advice when TB signs and symptoms are experienced. TB patients and survivors must be mobilized as they are in the best position to raise public awareness to end discrimination. This is stated in Section 10 of RA 10767.

• Health care workers must be equipped to provide quality compassionate care to all patients who seek medical assistance, especially those who require long-term care like TB patients. Section 6 of RA 10767 calls for education, training, and improvement of the skills of HCWs. This was also one of the recommendations of the 2016 National TB Prevalence Survey to promote adherence to treatment.

Physical Infrastructure

The DOH requires health facilities to install signages to facilitate navigation within the health facility. However, the key informants said that the signages foster discrimination. For example, if other patients observe you going to the area marked "DOTS" – short for TB Directly Observed Treatment-Short Course – you become identified as a TB patient and the other people steer clear of you. One suggestion for infection control purposes that will also help TB patients access the services that they need is to designate specific days and time for specific services. For example, Wednesdays are usually immunization days for infants and children, so TB patients can come at some other assigned time. Schedules can be prominently displayed outside the facility so that it will not be necessary to HCWs to personally inform TB patients in front of the public, breaching confidentiality in the process. Health facilities should observe visual and aural confidentiality for all patients, not just TB patients.

Two KIs were turned away from hospitals because HCWs claimed that they do not have a childbirth area for pregnant women with an infectious disease, nor the properly trained personnel. Contrary to what happened, hospitals must exercise universal precautions and provide for clients with infectious conditions. The needs of patients must be attended to without prejudice to other patients and HCWs.

Contraceptive Supplies and Services

Two KIs were pregnant while undergoing treatment for TB. The 2016 National TB Prevalence Survey recommends strengthening collaboration between the National TB Control Program and other health programs, specifically, HIV, diabetes, and smoking cessation. There is also a need to consider the reproductive health concerns of TB patients, particularly prevention of pregnancy and sexually transmitted infections. *The Companion Handbook to the WHO Guidelines for PMDT* recommends pregnancy testing for women because of the potential harmful effects of treatment on both the mother and baby. While there is no contraindication for the use of hormonal contraceptives, having to take more pills and/or injections might cause more discomfort and stress to the patients who are already burdened with so many pills and daily injections. Barrier methods like condoms and IUD might be more convenient and acceptable, keeping in mind the additional disease prevention benefits of condoms.

Livelihood Opportunities and Income Generation

The Philippines has a long and difficult history as a country with a high burden of TB. The 2016 National TB Prevalence Survey recommends "more comprehensive and sustained poverty alleviation efforts and multi-sectoral partnerships at the national and local levels." TB is not just a health issue; it is also a socio-economic issue. The KIs attest to the economic difficulties

they have had to deal with while undergoing treatment. The treatment and medicines are provided, but patients are unable to earn to meet their other needs, because they do not have work and income. There should be livelihood programs for TB patients and their families.

Florita Dalida, a nurse with Rogaciano Mercado Memorial Medical Hospital in Santa Maria, Bulacan was moved by the plight of her TB patients and their families. Dalida set up the TB Health Education and Livelihood Support Patients Alliance (TB HEALS) to advocate for TB patients' rights and raise public awareness of TB as a preventable and curable disease. TB HEALS recognizes that financial sufficiency raises patients' hopes and aspirations and gives them a fresh start on life. Now registered with the Philippines' Securities and Exchange Commission (SEC), TB HEALS started by soliciting sponsorship for the medical and hygiene supplies of patients. While plans for other projects (bag making, managing the hospital canteen, etc.) have been put on hold because of the COVID-19 pandemic, they hope to pursue these once restrictions are lifted. They say with conviction: *"It is our passion to serve with compassion."*

REFERENCES

Department of Health – National Tuberculosis Control Program. *Manual of Procedures for TB (DS & DR) and Latent TB Screening, Diagnosis, and Management*. 6th ed. 2020.

Department of Health – Disease Prevention and Control Bureau. *National Tuberculosis Prevalence Survey 2016 Philippines*. Manila, Philippines, 2016.
http://www.doh.gov.ph

RA 10767 - *An Act Establishing a Comprehensive Philippine Plan of Action to Eliminate TB as a Public Health Problem and Appropriating Funds Therefore* (2016)

World Health Organization. *Companion Handbook to the WHO Guidelines for the Programmatic Management of Drug-Resistant Tuberculosis*

World Health Organization. TB Care I. *International Standards for Tuberculosis Care, Edition 3,* TB Care I, The Hague (2014)

World Health Organization. *Patients' Charter for Tuberculosis Care* (2006) World Care Council/ Conseil Mondial de Soins www.worldcarecouncil.org/

TRIALS & TRIUMPHS

Action for Health Initiatives, Inc. (ACHIEVE)
Unit 201 Villasi Mansion, No. 160 N. Domingo Street,
Barangay Kaunlaran, Quezon City 1111 Philippines
achieve_hiv@yahoo.com
(+63-2) 83617980

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USAID leads international development and humanitarian efforts to save lives, reduce poverty, strengthen democratic governance and help people progress beyond assistance. USAID partners with the Philippines to drive inclusive economic growth and promote peace and stability. USAID builds the country's self-reliance by strengthening the Philippines's ability to plan, finance and implement its own development solutions.

Action for Health Initiatives (ACHIEVE), Inc. is a non-government organization that works on human rights, gender and other health and development issues affecting migrant workers, people living with and affected by HIV, and people affected by TB. Using rights-based, gender responsive and participatory approaches, ACHIEVE endeavors to directly involve communities in the planning, implementation, monitoring and evaluation of health initiatives.

The Philippine Alliance to Stop TB or PASTB was founded on April 23, 2021 by 18 founding civil society organizations across the Philippines. The founding members are composed of non-governmental organizations working nationally and locally, community-based organizations, peoples' organizations, and TB patient groups. The network was borne out of the need to have a truly people-centered TB Response in the country.