Article

SOCIOCULTURAL DETERMINANTS OF HEALTH-SEEKING BEHAVIOR AMONG CHILDREN LIVING WITH TUBERCULOSIS AND THEIR CAREGIVERS IN INFORMAL SETTLEMENTS

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Abstract: With urban populations increasing due to urban-centric development and with affordable housing remaining insufficient, a significant number of Filipino families have taken residence in informal settlements that are often situated in hazardous zones. Despite the ecological and health threats, children are forced into these circumstances by their dependence on their caregivers. The extent of their resilience and recovery from these threats are significantly determined by two contexts: the health-seeking behavior of their caregivers and the socio-economic roles that they are expected to perform as active contributors in their household's subsistence. Looking into one of the Philippines' top causes of children's mortality, pediatric tuberculosis, this paper discusses the forms of vulnerability and resilience that these children and their households negotiate with. Drawing from Cultural Epidemiology, this work presents the illness and well-being narratives of children with tuberculosis in three of Manila's largest informal settlements: Baseco Compound, Payatas, and Bagong Silang. Specifically, this work 1) identifies the socio-cultural activities that make children vulnerable to TB and 2) describes the household dynamics that define the health-seeking behavior of its members. Informed by these accounts of how families cope with the embodied effects of dispossession and structural violence, this work concludes by providing a critique of national development policies, which have continuously worked to deepen inequalities related to income and quality of life. Without a system that truly prioritizes the health, wellbeing, and education of all Filipino children, we can expect official promises.

INTRODUCTION

Tuberculosis (TB) remains to be an epidemic in the Philippines where recent surveillance data showed that it ranked 5th of the topmost causes of mortality (Department of Health, 2016). Children of half a million are diagnosed with TB, of which 200,000 led to death (Aldaba et al., 2018). Despite these staggering statistics, pediatric TB remains less recognized compared to the adult-form of TB. This is primarily attributed to its non-communicable nature. Recent reports have cited the significant increase of cases of pediatric tuberculosis in urban poor communities. Due to suburban sprawl, TB incidence is more concentrated in urban areas than the rural counterpart. The continuous expansion of urban areas have created "hazardous

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spaces" where public health facilities are limited (Smelyanskaya & Duncan, 2015). In urban informal settlements, pediatric TB is prevalent due to an intensified vulnerability associated with challenging socio-ecological conditions, such as poor ventilation and congestion. About 10% of the total population of children in the National Capital Region live in urban informal settlements are at risk of communicable diseases (C. Reyes et al., 2011). This is a clear threat to the attainment of children's wellbeing as inclusive of "happiness, satisfaction of needs and wants, and overall health" (UNICEF, 2014).

While there is an increase of pediatric TB cases that sets as a marker of a deficient health system in a community, limited research exists on such association (Peabody et al., 2005; K. Reyes & Amores, 2012). Remains to be implemented are strategic and culturally relevant efforts to address the TB epidemic in these marginalized areas. Pediatric TB receives insignificant attention as it has been overlooked in most of the TB control programs (Hodge et al., 2009; National Institute for Public Health and the Environment, 2016; Policy Cures, 2014). It is from this reason that this study looks into the narratives of children with TB (CLTB) in urban poor areas. This study covers the entirety of the illness narratives of the CLTB which range from their susceptibility to the disease to their actual access to healthcare services. Using the Explanatory Model Interview Catalogue (EMIC), this study provides an in-depth data of the informants' localization of the disease and treatment, specifically in urban poor areas of Baseco, Payatas, and Bagong Silang. The study argues that the health-seeking behavior of the CLTB and their caregivers are shaped by a weak political commitment of addressing health inequities which therefore constructed their vulnerability to TB. The study captures the practice of agency of both children and caregiver as they carry the burden of the disease. This study concludes with a reframing of existing policies on pediatric TB by highlighting the current disparities of the TB-DOTS programme in urban informal settlements.

TABLE OF ABBREVIATIONS

Abbreviation	Term
BCG Vaccine	Bacille-Calmette Guerin Vaccine
BHW	Barangay Health Worker
CLTB	Children Living with Tuberculosis
HCP	Healthcare Provider
MDR-TB	Multi Drug-Resistant Tuberculosis
TB	Tuberculosis
TB DOTS	TB Directly Observed Treatment Short-course

METHODS

Research Design

This study is qualitative in design as it employed key informant interviews, focus grouped discussions and observation. Data collection and inquiry were executed through fieldwork by focusing on a specific phenomenon for an in depth understanding of the setting, meanings and experience of the CLTB in urban informal settlements. These data collection processes were guided by the Explanatory Model Interview Catalogue (EMIC) of the Cultural Epidemiology Approach to understand the localized concepts of the disease and the associated health-seeking behavior of the informants.

Data Gathering Techniques

Non-probability purposive sampling was used as a sampling technique in this study. Informants are consisted of CLTB (aged 5-14 years old) and caregivers (aged 18 and above) (World Health Organization, 2014). A total of 50 partner (caregiver and children) informants and 10 healthcare providers (HCPs) which ranged from barangay health worker to medical doctor were interviewed per urban informal settlement. Due to data privacy in health centers, informants were selected through house-to-house method. Community members were informally asked about pediatric TB cases within the area. Informants were selected without prejudice of gender and ethnicity. The caregivers of the CLTB were informed about the scope and objectives of the study. Caregivers who are willing to

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participate in the study were asked to sign an informed consent, stipulating that their participation is entirely voluntary. For children who are unable to fully articulate on interviews, child-based activities such as playing and drawing, were conducted. Observation and field notes were done to determine the patterns of their everyday experiences as a TB patient. After finishing such, focus group discussion was held for data validation and community consultation. An audio recording device was used to document the proceedings.

Enumerators were asked to wear a disposable earlooptype mask as a medical protection from TB exposure. Daily vitamin C (500 mg) intake was used a prophylaxis during the entire duration of the fieldwork. Chest radiograph was done among enumerators to be certain of their health condition after fieldwork.

Data Analysis

Audio recordings were manually transcribed using Microsoft Word. After, the transcriptions were sorted and analyzed through a qualitative data analysis software – MaxQDA 2018. A set of codes derived from literature review was used for closed coding. Consequently, open coding was used when new themes and localized theories emerged during the coding process. From these codes, themes were created and validated with selected community members.

Ethical Considerations

Ethical clearance was obtained from the institutional ethics review committee of the University of Santo Tomas. Informed consent forms were given among caregivers of the CLTB. This informed consent was read to them, stating the purpose of the study, procedures to be undertaken, foreseeable risks, and its benefits in the community. It is here where they were assured that all the gathered information will remain confidential. The names of the informants were anonymized in terms of name and age. They were reminded that their participation in the study is entirely voluntary and that they may stop participating at any point if their side wishes. This study ensures that there was no physical and psychological harm that was involved to the subjects of the research and that all of them were treated with utmost respect.

RESULTS AND DISCUSSION

Socioeconomic Characteristics of the Informants

Rural-to-urban migration increases annually because of the prevailing perception that urban areas are the centers for development (Bagheri, 2012), job opportunities (Bolay, 2006), and education. With unaffordable housing options in the city, new migrants are forced to take cheap housing which are often located along government declared hazard zones. The three areas that are part of this study are situated in Metro Manila's hazard zones which includes a reclamation area, a dumpsite, and a riverside.

Apart from the constant danger posed by the varying elements like flooding and trash erosion, the residents are also facing other adverse conditions, such as but not limited to, poor sanitation, food insecurity, violence, and overcrowding. All of these contexts contribute to the general inability of the residents to attain a good quality of life. Most of the children that participated in this study were born in these locations and have been accustomed to these challenging environments. In an earlier work, children were noted to have a different perspective towards flooding such that the fear of contracting floodwater-borne diseases was lacking, and this was evident in the predisposition of these children to swim in disease-ridden water (Ancheta, Batan, Balita, Alejandria, In Press). This orientation is chiefly due to the normalization of hazard and neglect among children who were born into this environment. The want to attain a better standard of living is observable among the residents as aspirations to have land tenure, secure housing structure, and ultimately, formal education are part of daily conversations and engagements. However, relocation outside of their current area remains a contested option. The lack of economic opportunities in the new site and its distance from schools and other sources of basic needs deter the residents to move out of their current settlements. This gap in implementation of inclusive and sustainable urban planning added to other lapses in policies to promote inclusive societal growth. Prolonged residency in these conditions have established forms of engagements within the household, the community, and institutions. A child that contributes to the household's economy is common. A multi-generational household which at times skips the parental generation is common. A family that is diagnosed with the same communicable disease is common.

With households consisting of 4 to 7 members and that are typically dependent on a main single income, responses to health needs are often set aside to prioritize other basic needs such as food and water. However, this scenario grows dimmer when the primary earner is hit by an illness like tuberculosis which disables him/her to continue on with his/her livelihood.

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Living Conditions and Access to Healthcare Services in Urban Informal Settlements

The Case of Baseco Compound

Bataan Shipyard and Engineering Company or Baseco Compound is the largest urban informal settlement in Manila. This 52-hectare reclaimed area is surrounded by large bodies of water. The settlement is composed of individuals who are commonly from rural areas in search for job opportunities. While pavements at the façade are cemented, the setting is relatively different near the coastal area of Baseco. Narrow pathways are filled with layers of mud and waste materials. The area is vulnerable to storm surges and regular flooding which makes some areas submerged in knee-deep flood water for prolonged periods of time. Communicable diseases can easily be transmitted as houses have poor indoor ventilation. Among the (21) blocks in Baseco, block (9) is especially hard-hit by health threats. Aside from the congested houses here, the stigmatization that is associated in this block contributes to the increasing cases of communicable diseases. Healthcare services in this block are difficult to access as it is not frequently visited by service providers. In this study, 10% of the Baseco informants are from this block.

Only (2) health centers are shared by almost 60,000 residents of Baseco. Of these two (2), only Corazon Aquino Health Center has a TB DOTS facility. Although medical consultation and anti-TB drugs are free of charge, the increasing cases of TB in Baseco has forced patients to be referred to other distant public health units, such as Ospital ng Maynila and Gat Andres Bonifacio Memorial Medical Center. It is also in these public health units where laboratory services (chest radiograph, sputum test, tuberculin skin testing) are commonly accessed to determine their diagnosis of TB. These services, however, are not free of charge. This causes financial burden among caregivers as doctors frequently require patients to redouble their laboratory tests for the accuracy of their diagnosis.

The deficient healthcare services in public health units has led informants to rely on Missionaries of Charity or locally known as Alay ng Puso. This non-profit organization, located near Baseco, aims to address different health issues among urban poor, including pediatric TB. Missionaries from Alay ng Puso would roam around Baseco to observe children who have symptoms of TB and provide them with free laboratory tests. If diagnosed, Alay ng Puso covers the medicinal care of the patient for the entire duration of the treatment. The significant burden that the residents face in the process of TB treatment in public health units has been addressed by Alay ng Puso. It was found out that case detection is more emergent in the organization rather than the local TB-DOTS facility. The informants described the organization's system of healthcare as "mabilis and proseso" (fast process) and "tuloy-tuloy ang gamutan" (continuous supply of medicines). In some cases, children are obliged to live under the custody of Alay ng Puso to compensate their formal education and focus solely with their medication. The parents narrated how difficult it was to be physically detached from their children, but they had no choice as they are eager to cure them from TB.

The Case of Payatas

Payatas, as called as the "Smokey Mountain", is the largest dumpsite in the country. The barangay is divided into three: Payatas A, Payatas B, and Lupang Pangako. These divisions are based between areas that are developed and destitute. It was reported that only 20% of the total land area of Payatas are developed which is located in the Payatas A division (Sapientiae, 1998). Lupang Pangako, a place of over-filled dumpsites, is usually where low-income communities exist in. This is where overcrowded houses reside where basic social services are limited. The barangay, in total, has an increasing population rate because of the source of livelihood they get from pangangalakal or scavenging. It was still during the 1970s when the dumpsite started to operate. Although the government has already issued the closure of it for almost 2 decades, there are still numerous junk shops which operate within the area. Long time landfills were already rehabilitated by turning it into parks, yet air pollution remains to be a major threat. The smoke from burned brass and rotten smell of garbage are prevalent which may aggravate lung-related diseases.

Payatas has a corresponding health center for each of its divisions. Among the (3) health centers, Lupang Pangako health center has the greatest number of patients. This is also where majority of the low-income individuals seek treatment for TB. Laboratory services, such as tuberculin skin test and sputum test, are said to be available yet there are times in which patients are referred to other hospitals for this kind of tests.

As similar with Baseco, there are non-profit organizations that caters medicines for pediatric TB patients in Payatas. In a street located in Payatas B, Faithful Companions of Jesus (FCJ) is a renowned organization that provides free laboratory services and medicines for children. Although it only covers a small area of Payatas, the informants recounted

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The Case of Bagong Silang

Bagong Silang or Barangay 176 has a high population rate as it is known as the second largest barangay in the Philippines. It was recorded that the total population of the barangay encompasses 15% of the total population of the city. Comprised of (12) phases, Bagong Silang has become a relocation site for informal settlers across Metro Manila. Bagong Silang, which literally translates to "newborn", implies "new hope" for relocators who were deprived of land tenure from their previous location. A glimpse into the threshold of Bagong Silang will give an idea that the locale is not as unpleasing as any informal settlement because of the cemented pavement, concrete houses, and commercial hubs. However, in the narrow streets of the barangay, one could see the congestion and suburban sprawl that are concealed in the outskirts. Being a barangay that is bounded by a river in the north and west, shanty houses are seen beside cricks of narrow streets where settling in is hazardous. Inhabitants here are especially more deprived of accessing health services as the area is difficult to be passed by. Bagong Silang is also seen as a criminalized space because of the high incidence of child trafficking. Most of the informants recounted how Bagong Silang pose a major challenge to peace and security.

It was recorded that there are 6 health centers in Bagong Silang as it covers a population of almost 250,000 residents. Although all health centers have a TB DOTS facility, health center in phase 2 is known for their specialization for TB. This health center recognizes a health committee for TB that is known as the 'TB Task Force'. The role of this personnel is to promote training, service delivery, and advocacy that is related to TB. As an initial inquiry, health centers in Bagong Silang are efficient as it was found out that there are less than 20 pediatric TB cases in the TB master list of phase 2 health center from year 2017 until present. This was, however, not what it purports to be as a healthcare provider acclaimed that health centers in the locale do not prioritize pediatric TB. The available supply of anti-TB drugs are for the older adults. This is especially true based from the indications of the informants where majority of them access their medicines from private clinics because anti-TB drug syrups are not available in health centers.

German Doctors has also operated in Bagong Silang 3-5 years ago after their contract with Payatas. This organization was mentioned multiple times during interviews with caregivers. It had a positive portrayal in the community as it was described as "epektibo" (effective), "magaling ang mga doktor" (excellent doctors), and "madaming gamot" (many medicines). TB patients are commonly brought here to receive free consultation, laboratory services, and medicines. When it was still on its operational period, Bagong Silang was believed to be at its most efficient care among TB patients.

"*Sakit Sa Baga*": Localized Concepts Associated with Tuberculosis

Despite the campaign for health education under the TB DOTS program, there are still misconceptions about TB. The disease is familiar among informants yet their knowledgeability about it is considerably low. The normalization of it in urban informal settlements has shaped their understanding of its symptoms and transmission. Such understanding that the disease is a "normal cough" and must not be considered as "severe". Even given the diagnosis of "primary complex", informants have come to think that this term differs from TB. Some believe that primary complex is just a "mild" disease and that TB is an adult-form of disease. It is only from the adult-form of TB where the informants stated that the disease is "*nakakamatay kung hindi aagapan*" (deadly if not cured).

> **Caregiver:** *Wala. Hindi naman sila as in TB naman yung sa anak ko eh*. (None. My children do not have TB.)
>
> **Interviewer:** *Opo.* (Okay)
>
> **Caregiver:** *Yun. Kung pinabayaan, patungo na dun. (*If neglected, it will lead to it.)
>
> **Interviewer:** *Ahh ganun po yung* – (Ahh that's what you –)
>
> **Caregiver:** Parang yung kanya kasi primary complex ng baby. 'Di ba yung iba, normal lang yung nagkakaganun? (It's like primary complex – for baby. Isn't it for others, that's just normal?)

The discernment that TB is only severe when it is among older adults rather than children can lead to disparage of healthcare given to the CLTB. The low risk perception of the informants may cause postponements of diagnosis and treatment. Majority of those who sought healthcare reported that they were delayed on seeking diagnosis for their children because they did not foresee the symptoms of TB. There are caregivers who were surprised when they found out that their children have TB, as they see their condition as "parang walang sakit" (seem to have no

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disease). It was only during the aggravation of the disease where caregivers decide to seek check-up for the children. Chronic cough was the primary indicator of going to a health facility, & this was followed by fever and loss of appetite. In Baseco, high-risk symptoms of TB, such as vomiting or coughing of blood, are major markers of seeking treatment for the disease.

> **Caregiver:** *Pinacheck-up muna namin siya. Ubo. Ubo nang ubo. Binibigyan siya ng gamot ng doktor. Nung time na 'yun na nakita ko 'yung dura niya, dugo na talaga. Sinabi ko ('yun) sa doktor. Ayun, binigyan kami ng (request na) pang-x-ray. Nakita sa kanya (na may TB).* (We brought him for check-up. Cough. He always cough. He was given a medicine by the doctor. When I saw his sputum, it has blood. I told that to the doctor. There, he gave me a request for x-ray. The doctor saw that he has TB.)

The unsanitary environment in urban informal settlements has led informants to formulate that basura (garbage) and usok (smoke) are the main reason for having TB. This belief appears to be the topmost reason for the informants. Aside from this, some informants believe that dry sweat and change of season can also lead to TB. Children, as known to be active to outdoor activities, are believed to be receiving their disease from the external environment. This is especially common in Payatas as the place is occupied with landfill waste. Majority asserted that their living conditions in the locale has contributed to the development of TB.

> **Interviewer:** *Eh kayo 'nay anong alam niyong mga rason paano tayo nagkaka-TB?* (How about you, what do you think are the reason for having TB?)
>
> **Caregiver:** *Tingin ko dito *laughs*, dito sa lugar ganun. Siguro kung* – (I think *laughs* because of this place.)
>
> **Interviewer:** *Dahil sa Payatas?* (Because of Payatas?)
>
> **Caregiver:** *[…] malinis ka nga halimbawa sa loob ng bahay eh pag lumabas naman yung anak mo? Hindi naman natin pepwedeng i-ano lang sa loob ng bahay. Pag lumabas siguro nakakasagap din sila ng ano, ibang mga (madudumi) -- kung baga sa ano yung talagang maruming tinatawag.* (You are clean inside your house – for example, but what if the CLTB already go outside the house? We cannot just let them stay inside the house. When you go out, they can still suck up the dirt.)

Children who belong to a household that has an active TB patient affirmed that the disease is infectious. The informants narrated how the disease is obtained from either of the CLTB's grandparent or parent. There are instances where the caregivers themselves are the ones who have TB, yet they continue to take care of their children as the other household members are engaged in economic activities. Even if the children are in the process of treatment, TB can still occur as long as there is an active TB patient within the household. This just perpetuates cycle and aggravation of the disease.

> **Interviewer:** *Hmm. Bukod po kay Lindo po at sa inyo po nanay, meron pa po bang miyembro sa inyong pamilya ang may sakit po sa baga?* (Aside from Lindo and you, mother, is there any member of the family who has a lung-disease?)
>
> **Caregiver:** *Asawa ko. Sa kanya pa yata nga ako nahawa eh.* (My husband. I think I also got infected by him.)
>
> **Interviewer:** *Ahh yung nauna(ng nagkaroon ng sakit) po (ay) yung asawa niyo po.* (Ahh, your husband is the first one who got sick?)
>
> **Caregiver:** *Siya 'yung dating pinagamot ng magulang. Nandyan pa nga yung plaka nya.* (He is the first one to undergo TB treatment by his parents. His card is still there.)
>
> **Interviewer:** *Ahh siya po yung nauna po, nanay.* (Ahh. He is the first one.)
>
> **Caregiver:** *Ayaw naman magtuloy-tuloy ng gamot. Tamad uminom ng gamot yan eh.* (He does not like to continue his medication. He is lazy on drinking his medicines.)

Even if children are in the process of treatment, it can be inferred that they are highly susceptible to TB because their own caregivers are active TB patients as well. These caregivers would focus more on the health needs of their children rather than themselves. This may form another cycle of treatment which can lead to Multidrug-resistant

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Tuberculosis (MDR-TB) – a type of TB that is resistant to treatment of the first-line anti-TB drugs. Acquisition of such disease may decline the likelihood of curing the patient from TB. Another concept of TB for some informants is that the disease is hereditary. As CLTB usually belong to a family that has a history of TB, the assumption of the caregivers is that the disease is based on inheritance. This belief disregards the practice of infection precaution as it permits close contact to an active TB patient.

Interviewer: *Sa tingin niyo po, ano po yung naging sanhi po ng pagkakaroon ni Daniele dati ng primary?* (For you, what do you think is the cause of Daniele of having primary?)

Caregiver: *Lahi. Kasi lahi rin namin yun.* (Breed. It's in our breed.)

Interviewer: *Ahh, sa lahi, so bukod po kay* – (Ahh, breed, so aside from –)

Caregiver: *Sa side ng father ko.* (In my father's side.)

For the perspective of the CLTB, a child with a disease is commonly inside the house. Describing it physiologically, such as nakahiga lang (just lying down), inuubo (coughing), masakit ang dibdib (chest pain), and nahihirapan huminga (difficulty of breathing). Also psychosocially, such as hindi nakakapaglaro (unable to play), nasa loob lang ng bahay (just inside the house), and malungkot (sad).

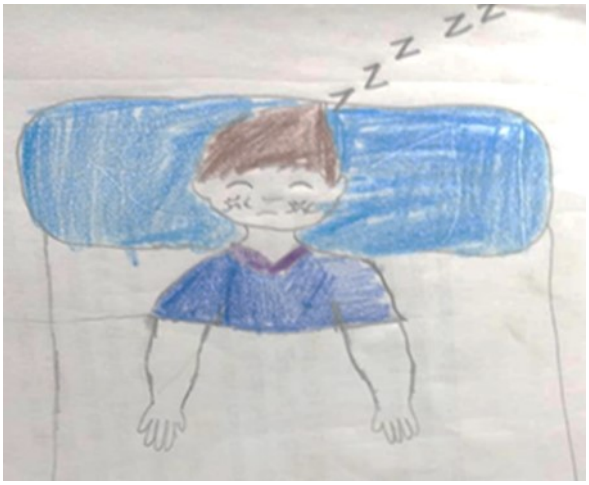

Figure 1 - The CLTB's concept of an unhealthy child

Defective Health System

Ever since the espousal of the Millenium Declaration, healthcare has been an important agenda in the Philippines (Department of Health, 2014). This has also resulted to the decrease of TB cases of more than half between 1990 to 2015. Although much has been achieved to date, redoubling efforts are still needed to alleviate TB epidemic. Directly Observed Treatment Short-course or TB DOTS, as a core strategy of the National TB Control Programme, is branded as an "internationally recommended, highly efficient and cost-effective strategy" (World Health Organization, 2011). However, there are still lapses that need to be addressed in this program, most especially that the present health budget was cut down into 8% and the TB budget to almost 50% (Department of Budget and Management, 2019). This may lead to immobilization of healthcare services and out-of-pocket expenditure from individuals.

Interviewer: *Bale, paano niyo po mailalarawan po 'yung proseso ng isang tagapag-alaga pong batang may sakit po sa baga?* (How would you describe the process of a caregiver to a child with a lung disease?)

Caregiver: *Sa mahirap na pamilya, mahirap.* (In a poor family, it is hard.)

Interviewer: *Mahirap po.* (It is hard.)

Caregiver: *Pero kung sa may pera ka, hindi mahirap.* (But if you have money, it's not hard.)

Interviewer: *Paano niyo po nasabi 'yun, 'nay?* (Why did you say so?)

Caregiver: *Kasi kung mahirap ka, pipila ka.* (Because if you are poor, you will fall in line.)

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Interviewer: *Hmm. Sa gamot?* (Hmm. For medicine?)

Caregiver: *Pipila ka sa gamot. 'Yung tustusin mo sa pagkain, vitamins, (at) laboratory (services) kung may ipapagawa sila. (Mahirap) lalo na't kung wala ka talagang pera.* (You will fall in line for medicine. The expenses for food, vitamins, and laboratory services if they need to do something to you. It's hard, most especially if you do not have money.

Deficient Information Dissemination

Public education plays an integral role on encouraging individuals for case detection and treatment & reducing TB-related stigma. Standardizing health education and dissemination have indeed an impact to the decrease of TB cases. In this study, interviewed healthcare providers (HCP) confirmed the presence of education and communication strategies for TB control of their respective health centers. Partnered non-profit organizations has helped local health centers to provide information about TB among barangay health workers. Baseco works with Philippine Business for Social Progress (PBSP), Payatas with Quezon City Health Department, while Bagong Silang with World Vision. Health workers and community workers were trained to roam around to educate residents about TB, encourage them to undergo laboratory tests, and follow up patients who missed their medication. Although it is true that these happen, not all areas are covered by such. Nearly all informants claimed that there were no signs of health education about TB within their area. If there is, it only happens in health centers, when TB patients will start the course of their treatment. This then perpetuates hesitation, most especially among children, to seek treatment because of the difficulty of confirming the disease.

For the CLTB who are already in the process of their medication, some were mistaken of their medication. There are CLTB who stopped the intake of their medicines, yet health workers were not able to follow them up. Instead of finishing the standard treatment, their failure to drink medicine may increase their drug resistance.

In Payatas, there are (4) cases of incorrect prescription given to children. They were prescribed with anti-TB drugs even if their laboratory results were negative. Of these (4), (3) of which have cases of pneumonia and both were prescribed with anti-TB drugs with the belief that it can cure them from their disease. The other one, on the other hand, was given an isoniazid which resulted to side effects like trembling of body. These informants, without further hesitation, believed to this instruction as they put their trust to health professionals of providing them accurate healthcare.

Another problem that was identified is the misinformation of barangay health workers about TB. Most of them perceive that TB is caused by vices (i.e. smoking and alcohol consumption). Although it is true that such may intensify the disease, this information, however, might contribute to prolonged delay of seeking medical care, most especially among children. This information may hinder children of having medical consultations because of being uncounted of smoking and drinking of alcohol.

Interviewer: *Sa tingin niyo po, bakit mas mataas yung kaso ng mga matatanda na may TB kesa sa bata po?* (In your own view, why do you think there are many cases of TB among older adults rather than children?)

BHW: *Ang matatanda kasi dito abuso sa katawan. Yung iba malakas mag-inom, malakas manigarilyo. Tapos polluted pa yung area kasi malapit sa basurahan.* (The older adults here are abusing their body. There are some who drink a lot, smoke a lot. Also, the area is polluted because we are near the dumpsite.)

Shortage of Anti-TB Drugs

One of the five elements of the TB-DOTS is the constant supply of quality-assured anti-TB drugs in healthcare units (Department of Health, 2016). This must be given for free among diagnosed TB patients to reduce out-of-pocket expenditure. Despite this goal, shortage of anti-TB drugs is still a chief problem in all health centers of the research sites. There are instances wherein patients are given an incomplete set of anti-TB drugs because of unavailability. This then forces the patient to spend their own money on buying anti-TB drugs because any interruption of medicinal intake may nullify the whole course of the treatment.

Anti-TB drugs for children are overlooked in health centers because older adults are said to have more cases of TB rather than children. As children do not have a vast role in the transmission of the disease, healthcare providers would focus more on providing anti-TB drugs among older adults. There are instances in which patients were given prescriptions for them to buy anti-TB drugs in drugstores. In the case of Bagong Silang, informants claimed

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that there was no available anti-TB drug syrup in health centers. Only (1) of the (50) CLTB was able to receive an anti-TB drug syrup. Some of the CLTB were prescribed with anti-TB drugs for adults and were just instructed to dissolve such in a boiling water. As the dosage of this medication differs from the adult form of anti-TB drugs, this may result to unbalanced treatment. In Payatas, this is also the case of a caregiver as his child was used as a trial to see if the anti-TB drugs for adults will be effective among the CLTB.

Caregiver: *Tapos 'yung sa ano naman… 'yung sa Rifampicin naman sa kanila kasing laki ng Salbutamol na maliit.* (Then the Rifampicin is as big as the small Salbutamol.)

Interviewer: *Hindi po syrup?* (It's not syrup?)

Caregiver: *Hindi ma'am eh. Naubusan kami ng stock nun.* (No, ma'am. It was out of stock.)

Interviewer: *Kasi po pag bata talaga, syrup po talaga yung pinapainom.* (Because if it's for children, it really needs to be syrup.)

Caregiver: *May time na may syrup doon. Hindi kami (nakakuha). First time ipinatry yung tablet sa center. Kami 'yung first time na nagtablet.* (There was a time that there was a syrup. We were not able to get one. It was our first time to try the tablet in health center. We were the first one who tried drinking a tablet.)

The mismanagement and shortage of anti-TB drugs in health centers have led majority of the caregivers in Bagong Silang to use out-of-pocket payments to make sure of the completion of treatment of the CLTB. This outlay also include laboratory tests, hospitalization, and over-the-counter medication like vitamins. In Baseco, access to anti-TB drugs were mainly from Alay Puso, a non-profit organization. Some informants had their medical consultation at the health center, yet they selected Alay Puso as a health provider because of its efficiency of providing medicines. The informants did not encounter any problems from the organization unlike with their experience with health center. This is the case in an area in Payatas where they access their medicines from a non-profit organization as well.

Caregiver: *May gamot daw dun sa center pero hindi tuloy-tuloy. Malay mo raw, kung wala silang gamot, sabi nito, eh wala naman akong pambili. Sabi ko kay Dr. Simon, "Dr Simon, doon ko na lang (ako kukuha ng gamot) sa madre". Sabi niya, "sige, sige, kung tutulungan ka ni sister." Ayun, dinala ko rin sa madre.* [There is a medicine in the health center, but it is not continuous. Who knows, there are no available medicines. I do not have any money to buy such. I said to Dr. Simon, "Dr. Simon, I will just (get medicines) from the nun". He said, "okay, okay, if the nun will help you." There, I brought (my children) to the nun (Alay Puso).]

Despite TB-DOTS, anti-TB drug management is still a challenge in public health units. Political commitment on systematic distribution of healthcare services is still substandard. National and local government place a minimal emphasis on pediatric TB as children do not contribute much to the transmission of the disease. Non-profit organizations, in turn, fill the gap that was left by the government to avoid interruption of treatment among CLTB. These organizations became active providers of healthcare services which made informants rely to their services instead.

Transport Difficulties

Transportation is a requirement for an ongoing healthcare. However, the rapid population increase and unpaved road infrastructure in urban informal settlements have contributed to barriers of access to healthcare services. Such barrier exacerbates the health condition of the CLTB as it causes delays on medicinal intake, laboratory tests, and consultations. Aside from the unreliable transportation, this also entails time, exhaustion, and additional expenditure among informants.

In all research sites, the common mode of transportation is tricycle. Although easily accessed because of its great quantity, transportation fare poses a financial risk among informants as it is not covered by the TB-DOTS. Transportation fare ranges between Php 50 – Php 150, which is a large cut to the daily income of the informants. Even if anti-TB drugs are free of charge in health centers and non-profit organizations, out-of-pocket expenditure on transportation is unavoidable as most of the informants are distant from health centers. With informants who do not have the financial capability to spend on transportation, they endure the heat and long-distance walk just to avoid interruptions on medication among the CLTB. This is worse in the inmost parts of the urban informal settlements where substandard road infrastructures are apparent. In the case of Baseco, it entails 30 to 40-minute walk

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to arrive at the health center, coming from the inner parts of the area. This walk requires passing mud-layered pavements and garbage.

Caregiver: *Kasi medyo malayo rin. Nilalakad ko lang. Hindi naman kasi nakakapasok doon 'yung tricycle.* (Because it's a bit far too. I just walk. The tricycle cannot pass there.)

Mismanagement of Human Resources

Philippines is one of the utmost exporters of health professionals globally, yet shortage of staff remains to be a problem within the country. This is especially the case in public health units where only 30% of the country's health professionals are employed by the government. This has placed the burden among patients as only a limited number of healthcare providers can cater their health needs. In all research sites, it was found out that each health center has only one physician who covers a great number of patients. The doctor-patient ratio remains to be imbalanced as many informal settlers are desperate of free healthcare services. This then resulted to informants, waiting and lining up for hours with no assurance of medical consultation and medicines. In Bagong Silang, although it has the largest number of health centers in all research sites, some of it do not open day-to-day. It was said that medical consultations are only possible for twice or thrice a week. The informants, as such, are forced to either wait for the time that the local health center will be open or go to other health units where they can access healthcare services.

Caregiver: *Sasabihin daw nila na Miyerkules-Huwebes, wala naman din.* (They said that Wednesday to Thursday but there is none.)

Interviewer: *Ahh, may schedule po pero minsan wala din naman pong doctor?* (Ahh, there is a schedule but sometimes the doctor is not around?)

Caregiver: *Opo, sasabihin nagmeeting daw 'yung doctor. Biruin mo every ano – meeting. 'Tsaka 'di pwedeng magpacheck-up 'yung taga dito na pupunta ka doon. Eh ano hihintayin mo 'yung… 'yung magkasakit ka ng araw na 'yun?* [Yes, they said that the doctor has a meeting. Imagine that, every (time we go there) – meeting. Also, we, who live here, are not allowed to have our check-up (in other health centers). So what, we will just wait for the time that we will get sick?]

The large number of patients in health centers cause concurrent stress to healthcare providers as well. The clamor of patients who are in desperate need of healthcare services becomes the everyday apprehension of healthcare providers. This is especially the case of barangay health workers (BHWs) as they are the carrier of anti-TB drugs among patients. Most of the BHWs are said to be volunteers and works for a long period of time because of the shortage of staff. Most BHWs have worked in health centers for almost a decade because of upholding their virtue of "kawanggawa" or the practice of charity. In turn, they receive an inconsiderable amount of money, ranging between Php 500 to Php 1,000 per month. For this reason, the unrelenting stress that the HCPs feel at work impacts the attitude they give to patients. Such attitude of being ill-tempered and irritable makes informants not adhere to medical consultations in health center.

Caregiver: *Masusungit. 'Pag hindi mo sila tinawag, hindi ka pa papansinin.* (Snobbish. When you do not call them, they will just ignore you.)

Interviewer: *Ahh talaga po?* (Really?)

Caregiver: *Masungit pa yung ano nagtatawag. Lalo 'pag OPD. Nako! Ayoko na.* (The person who calls the patient is snobbish too. Most especially when it's OPD. I do not want anymore.)

Interviewer: *Kaya hindi na po kayo (pumunta doon?) Isang beses lang po kayo pumunta doon?* (That's why you did not go back there anymore? You only went there once?)

Caregiver: *Dalawa.* (Twice)

Interviewer: *Dalawa *chuckles*.* (Twice)

Caregiver: *Ayoko na.* (I do not want anymore.)

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Patron-Client Relationship

It is designated in the TB-DOTS program that access to high-quality diagnosis and medication must be universal (World Health Organization, 1999). Proper management system and equitable distribution of health services must be given for all detected cases of TB. In other terms, there must be no patient preference who can solely benefit the available health services in local health centers. Allocation of healthcare services must be fairly distributed, without prejudgment of age and socioeconomic status. Political patronage, however, is an inherent feature in local health centers. Health workers in this study have cases of dyadic ties among TB patients who are commonly their acquaintance or kin. A health worker (patron) uses his/her position to provide "special" treatment among those who he/she only wants to be provided with healthcare (client), while leaving other patients – far-off of these health services (Colonnelli, Teso, & Prem, 2018). The mutual arrangement between the patron and client is an ever -present phenomenon as both parties are provided with benefits. The patron, as a sponsor, is provided with greater power and good impression while the client, as a recipient, is provided with goods and services. Due to the aforementioned problems on TB- drug and staff shortage, this arrangement is common in local health centers and it disproportionately affect the access to healthcare services among TB patients who rely such treatment here.

Pain in Silence: The Role of Caregivers

Informal caregivers, such as parents and siblings, are integral contributors to the healthcare process of the CLTB as its role encompasses a variety of experiences and situations. It is from this role where the practice of agency is heightened among them as they face day-to-day responsibilities to ensure the quality of healthcare given to the CLTB. Such responsibilities that cause burden because of the competing priorities that the caregivers need to perform. For this reason, majority of the informants claimed that the process of being a caregiver is difficult. This experience impacts their physical and emotional well-being. Physical, in a way that their energy is fully exerted to the CLTB that causes a large disruption from their engagement on economic and household activities because medication for TB not only requires adherence to drug regimen but also long-term monitoring. This includes accompanying the CLTB to school, getting of medicines, preparing meals, and other treatment-related activities. Some of the caregivers narrated that in order to focus on taking care of the CLTB, they had to stop their occupation.

> **Caregiver:** *Kung magtratrabaho ako, sino magpapainom sa kanya? Kaya hindi muna ako bumalik sa trabaho.* (If I will work, who will give him medicines? Hence, I temporarily did not go back to work.

Majority of the interviewed caregivers are mothers. As women, they express a greater sense of altruism because of the social connectedness they felt for whom they provide care. They are more engaged on providing healthcare for the CLTB rather than the men counterpart. The social identity of women in the household is built around caring which might cause a role-strain in their social life.

The caregivers were asked about their reaction upon knowing the diagnosis of the CLTB. As majority of the caregivers did not foresee the disease of the children, responses yielded similar information. They felt pangamba (terrified), gulat (shocked), lungkot (sadness) and kaba (nervous). In majority, it showed that they were not expecting the diagnosis of the CLTB. Such reactions caused emotional distress because of the obligation they need to uphold as a caregiver. This then leads to total disregard of one's health, most especially that some caregivers are also in the process of treatment. They would prioritize the treatment of the CLTB rather than themselves. Despite this, caregivers endure the burden because of their idea of responsibilidad. Translated to "responsibility", this term upholds more meaning than its actual translation. Responsibilidad does not only imply the duty that comes from kinship but more of a sense of empathy that draws them to action. This term connotes the prioritization of "them" rather than "me". It is from here where caregivers are "invisible patients" such that the suffering of others is their suffering as well.

Household-Based Dynamics that Define the Health-Seeking Behavior of the Informants

The difficulty of confirming the disease because of the non-apparent symptoms of pediatric TB has led to treatment delays among the CLTB. It is only during the aggravation of the disease or as described as matindi (severe) and matigas (stiff) where they seek medical treatment. Most of the informants initially visited the health center but due to its deficiencies, caregivers have practiced self-medication and rely their healthcare in private clinics, non-profit organizations and traditional healers. Adherence to drug treatment is the initial action of most informants upon knowing the diagnosis of the CLTB. Caregivers would force the CLTB to drink their medicines despite its bitter taste which is described as nakakasuka (nausea). Drinking of non-TB drugs, such as amoxicillin and carbocisteine, has also been an alternative medication for the CLTB who do not have access to anti-TB drugs. As the disease is normalized in urban informal settlements, caregivers would resort to low cost medicines, believing that these would treat the children from TB.

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Self-medication is much evident in Bagong Silang as there is a limited prioritization of pediatric TB in health centers. For this reason, the medication of the CLTB is not under the National TB Control Programme which would lead them to formulate their own meanings of the disease. It was found out that after the standard treatment of the CLTB, most of them did not undergo a laboratory test. Caregivers just inferred that the CLTB is already cured after the standard 6-month treatment. Avoidance of laboratory tests can result to TB relapse because the post-diagnosis of the patient is indeterminate. Another intriguing case in Bagong Silang is the inconsistent intake of anti -TB drugs of an informant. The caregiver, believing that anti-TB drugs can be drank uninterruptedly, only allows the CLTB to consume such if there is the presence of symptoms. Such practice may lead to drug resistance of first line of anti-TB drugs and exacerbation of the disease.

Caregiver: *Oo, ako na lang mag-isa nagpasya nun eh *chuckles*. Hindi ko na dinaan sa doctor kasi alam ko na may primary (complex) siya eh.* (Yes, I am the one who decided *chuckles*. I did not go to the doctor because I know that he has a primary complex.

Interviewer: *Kumbaga wala na pong, ahh, parang nagfollow-up po sa inyo ganun po?* (In other words, there was no follow-up from them?

Caregiver: *Wala na. Hindi na ako - wala nang follow-up follow-up sa akin. Basta alam ko na, ano ko na iyon primary. Eh yung kapitbahay ko iniinom din ay rifampicin, eh 'di bumili na lang din ako rifampicin tsaka isoniazid. Meron nga sa bote yun.* (None. I did not – there was no follow-up. My neighbor drinks rifampicin so I also bought rifampicin and isoniazid. There is a bottle of that.

As some informants perceive that TB is obtained from a filthy surrounding, they believed that cleaning of house can help the CLTB be treated from the disease. Caregivers would demand the children to not go outside because of the alikabok (dust) and basura (garbage). For some of the caregivers who believed that TB is infectious, the CLTB practice the usage of mask and own utensils to prevent the transmission of disease from the other household member.

Childhood Battle against TB

TB can be transmitted among children as early as less than one-year-old. Although this is preventable because of the innovation of Bacille Calmette-Guerin (BCG) vaccine, there is still a high percentage of acquiring TB in urban poor areas such that the disease is widespread and children commonly belong to a household that has an active TB patient. Almost all the interviewed CLTB have been injected by BCG yet this vaccination is still not sufficient to cover the vulnerability of the children to TB.

A child must be "provided a contextual understanding in different domains such as health, material well-being, education, conditions of housing and environment, and interpersonal relations" (United Nations International Children's Emergency Fund, 2014). This then means that children must be free of any difficulties that will disintegrate their childhood phase. It is challenging for the CLTB, however, to attain such because of structural barriers that avert them from enjoying this phase. As childhood is the most gratifying phase in any individual's life, the CLTB choose to hide their health condition because of the day-to-day stigmatization and discrimination they need to face towards their peers and neighbors. Challenged with prejudices, there are contexts of avoidance and intimidation that were felt by the CLTB within their social environment. Caregivers, in return, experience feelings of guilt because of initially disregarding the symptoms of TB among the CLTB.

Interviewer: *'Di alam ng mga classmate mo, ng mga kalaro mo na may sakit ka? Ba't hindi nila alam?* (Your classmates and playmates did not know that you have a disease? Why did they not know?)

Child: *'Di ko sinabi.* (I did not tell them.)

Interviewer: *Ba't hindi mo sinasabi?* (Why did you not tell them?)

Child: *Nahihiya ako pagtawanan ako.* (I'm shy because they will make fun of me.)

The CLTB, however, cross over the constructed representation of the disease as they practice their agency as a child. The CLTB uphold social relationships with their peers through social interaction and child-based activities. Most of the caregivers affirmed that there was no difference with the CLTB's daily activities between before and during medication. The CLTB endure the discomfort of their disease for them to be in line with other children

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who do not suffer from such. This is done through their participation in household-based activities and continuance of formal education despite of their on-going treatment. Caregivers choose not to disclose the health condition of the CLTB to their teachers to not discharge them from going to school. In turn, however, the CLTB's academic performance was affected because of the displaying symptoms of TB. Absences often happen because of their engagement to TB-related treatment. In a case of an informant, despite the caregiver's willingness to send the CLTB to school, there are instances where the CLTB refuses to because of the physical abuse he receives from his classmates.

Interviewer: *Bakit inaaway ka ba pag may sakit ka? Hmmm anong... anong ginagawa nila?* (Did they fight you when you are sick? What do they do?)

Child: *Minsan po sinusuntok. (*Sometimes they punch me.)

Interviewer: *Sinusuntok ka? Kasi may sakit ka daw? Hmm. Anong alam nilang sakit mo? (*They punch you? Because you have a disease? Hmm. What do they know about your disease?)

Child: *Wala po.* (None.)

Interviewer: *Ahh hindi nila alam kung anong sakit mo basta kapag nakikita nilang may sakit ka, sinusuntok ka. Ganun? Inaasar ka ba nila?* (Ahh, they did not know about your disease but when they saw you sick, they punch you? Like that? Do they bully you?)

Child: *Opo.* (Yes.)

Interviewer: *Hmm. Pag ganun ginagawa nila, anong naiisip mo?* (If they do that, what are you thinking?)

Child: *Wala lang po. Hindi ko lang sila pinani, ginagantihan.* (None. I just do not do it in return.)

In urban informal settlements where economic capital is difficult to attain, several CLTB assist on the livelihood of their parents to earn additional income. The CLTB would accompany their parents to work and also for the parents to watch over the CLTB. If not through economic activities, the CLTB engage on household-based activities to lessen the burden of responsibilities of the caregivers. This includes paghuhugas ng plato (washing of dishes), paglalaba (doing laundry), paglilinis (cleaning), and pag-iigib ng tubig (fetching water). The CLTB, despite of their health condition, are accustomed on doing such activities because they were taught to be independent in the face of urban poverty.

"Malusog Na Bata": Local Markers of Wellbeing

It was discussed that the indicators of TB for the informants are chronic cough, fever, blood in sputum, and loss of appetite. As such, when these symptoms are no longer observable, the informants believed that the CLTB are already "well". This was also their assumption before the CLTB undergo the standard TB treatment in which they only had their medical consultation when symptoms are apparent. During the onset of medication, some caregivers did not comply with the 6-month duration of medicinal intake because as through the half of the treatment duration, symptoms are no longer visible. This has led them to such thinking that the CLTB is already well. There are also instances where the CLTB did not undergo laboratory tests after the standard treatment because of this assumption.

"Graduate na" (I already graduated) is a common phrase, used by the informants to indicate that a TB patient has finished the treatment regimen for TB. The daily consumption of anti-TB drugs serves as their homework that is required to be drank to get rid of TB. As a graduate individual often feels contentment, this is also what informants the feel after the six to nine-month duration of treatment. The laboratory result serves as their "certificate" that they are free of TB.

The concept of wellbeing for children is based on environmental conditions. Such that the playground, the outdoor setting, is believed to be where the children are if they achieved well-being. This playground is designated as the opposite of the characteristics of an urban informal settlement, where it is "malinis" (clean) and "may puno" (there are trees). It is also in this space where the CLTB are given the opportunity to do such things that they were not able to do before. This is where they felt liksi (agile) lakas (strong), and saya (happy); as they can already interact with their peers, without facing stigma and discrimination.

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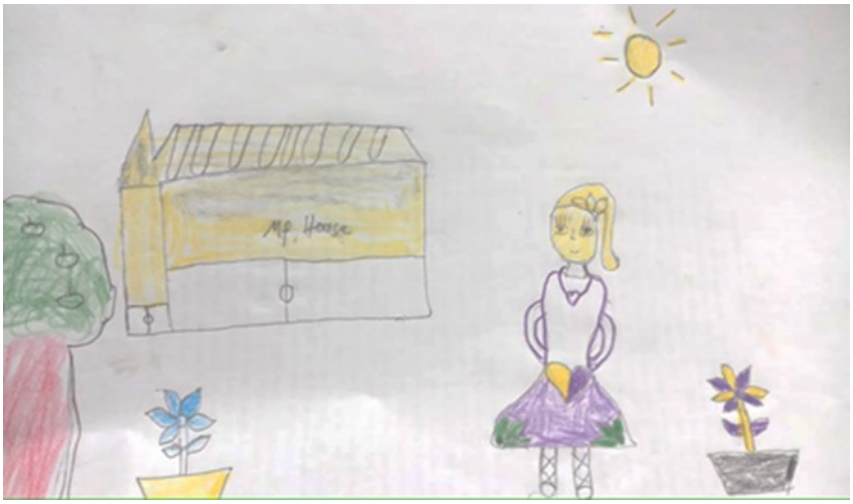

Figure 2 - The CLTB's concept of a healthy child

CONCLUSION

TB is a product of poverty that continues to bring the heaviest burden among the urban poor. As a structural trend in urban informal settlements, this communicable disease is rooted from socioeconomic disparities. Vulnerability to TB is intensified among children as focus is given more to the adult-form of TB rather than pediatric TB. Due to the non-apparent symptoms and restricted role in the transmission of disease, the CLTB have gone vast neglect in the health sector which reinforces stigma and discrimination among them. The caregivers have similarly become "invisible patients" as they exercise their responsibility to address the healthcare needs of the CLTB. The localized concepts of the informants with TB, such as "mild disease" or "normal cough", have shaped their health-seeking behavior which may lead to an on-going transmission of TB in urban informal settlements.

Access to healthcare services remain to be inequitable because of the constant mismanagement of health services and staff. Such barrier distances the community to local health centers and rely their health services to non-profit organizations instead. These organizations take ownership of the burden of TB in urban informal settlements as health services here are said to be more efficient rather than of local health centers. The findings of this study highlight the weak political commitment of the government on TB control. Strategic efforts for ending TB epidemic is not translated into policy formulation as TB-DOTS facilities in urban informal settlements face issues, such as but not limited to, deficient education promotion and shortage of anti-TB drugs. It is from this reason that the World Health Organization's designation of TB-DOTS as a "highly efficient and cost-effective strategy" is not pronounced within these areas as majority rely solely their healthcare to agencies and private clinics. TB-DOTS must extend its healthcare services among children as they are the most deprived of attaining such. Strengthening of community-based healthcare services must be also done to eliminate TB-related stigma.

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