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## Challenges Faced by House-Hold Contacts of Pulmonary Tuberculosis Patients In An Urban Setting In Nairobi, Kenya

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### ABSTRACT

Close contacts of active pulmonary tuberculosis (PTB) patients are at higher risk of infection as the confirmed cases remain highly infectious before and while in the early stages of treatment. This work highlights the encounters and perspectives of household contacts (HHCs) of PTB patients in an urban setting in Kenya, with a focus on accessibility to health services, interactions within the community, and the risk of infection at home. A multimethod study design involving descriptive cross-sectional analysis and informal interviews was used. The study participants were recruited from tuberculosis (TB) isolation wards and outpatient clinics of Mbagathi County Hospital in Nairobi, Kenya. Data was collected using structured questionnaires and informal interviews. Results revealed improved access to treatment by PTB patients. However, the global goal of eliminating TB infections by minimizing latent tuberculosis reactivation remains a challenge in this population primarily because most of the HHCs lacked knowledge on diagnosis and treatment of latent tuberculosis infection (LTBI). Most participants were residents of informal settlements in Nairobi characterized by small and poorly planned housing structures with poor waste management systems. In most houses, the living space doubled as cooking and sleeping area. There was therefore a high exposure of spouses, children and other persons living with the patients. We recommend that further education be provided to HHCs to increase awareness on available testing and preventive treatment for LTBI, and infection prevention practices at the household level. Furthermore, additional resources should be offered to economically disadvantaged patients to support their social and treatment needs.

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### Introduction

Tuberculosis is an infectious disease caused by *M. tuberculosis*, an acid-fast bacillus that is transmitted primarily by inhalation of infectious droplet nuclei. Due to the mode of transmission of the pathogen, individuals who are close contacts of persons with active PTB have a higher risk of infection as the confirmed cases remain highly infectious before and while in the early stages of treatment.

The World Health Organization (WHO) has classified TB as one of the top 10 causes of death worldwide and the leading

cause of death from a single infectious agent, ranking above HIV/AIDS. Several studies have been conducted in high burden TB areas to identify determinant factors associated with TB in adult populations and they can be broadly categorized as environmental, socioeconomic, and host/pathogen genetics [1].

Individuals who are predisposed to infection due to prolonged exposure periods include healthcare workers, HHCs, schoolmates, and workmates [2]. The HHCs are the primary caregivers of the patients while they are at home, and subsequently, have a higher

cumulative exposure to *M. Tuberculosis* through close physical contact and social interactions. In this report, we explored the level of awareness on LTBI diagnosis and treatment among HHCs of PTB patients and document their experiences of living with and caring for PTB patients at home. The data will be useful in identifying important gaps that could inform policies and strategies for TB prevention strategies at the household level.

### Methods

**Study Site:** The study participants were recruited at Mbagathi County Hospital in Nairobi, Kenya. It provides broad range of services that include an outpatient clinic and in-patient wards for PTB patients. The majority of the patients are from Kibera slums, the largest informal settlements in Africa.

**Study Participants:** The PTB patients were diagnosed by chest radiography, smear microscopy and GeneXpert at Mbagathi Hospital. Household contacts were defined as individuals who were living under the same roof with a PTB patient and have a common living room and cooking arrangement. Household contacts were approached during ward visits and at the outpatient clinic as they accompanied their patients. Participants were informed about the study, and those who gave their approved consent were recruited.

**Study Size:** One hundred and sixty six (166) TB patients were identified and from these, 175 HHCs who agreed to participate in the study gave their informed consent and were recruited. A structured questionnaire was used to record data on socio-demographic characteristics of the study participants. Informal interviews of individual HHCs for supplementary information on their experiences and clinical data was abstracted from the patient files.

**Study Questionnaire:** The structured questionnaire was designed to evaluate likely risk factors for LTBI based on published literature, and also included open ended questions to capture individual perspectives of the study participants on care of PTB patients. It was piloted on 10 participants before being used in the study during which all ambiguous questions were reframed for clarity.

**Study Design:** This was a multimethods study that involved a descriptive cross-sectional study design and informal interviews. Data was collected through structured interviews guided by a questionnaire and through unstructured conversations where the participants shared their experiences living with and caring for a PTB patient at home.

### Results

**Socio-Demographics of the Household contacts of PTB patients:** A total of 175 HHCs of 166 PTB patients were recruited. Most of the HHCs [65.7% (115/175)], shared a one or two-roomed house with the patient and 0.03% (5/175) of them had more than one PTB patient in their household. Of the total participants, 11.4% (20/175) were spouses of the PTB patients while the rest were siblings, members of extended family, or friends. The majority of HHCs were female 70.3% (123/175) and those in the productive age of 30-39 years were 37.7% (66/175). Regarding schooling, most of the participants [96.6% (69/175)] had attained formal education with 26.3% (46/175) attaining college-level education. Only 39.4% (69/175) were employed although most were on casual terms. History of cigarette smoking, alcohol consumption, and HIV seropositivity was reported among 5.1% (5), 16.6% (29/175), and 9.1% (16/175) of HHCs respectively.

**Perspectives of the PTB patients:** About 82.5% (137/166) of the patients indicated they had access to information on PTB, while 79.5% (132/166) and 83.1% (138/166) had easy access to the diagnostic center and prescribed medication respectively. Access to adequate nutrition was 82.5% (137/166), while support from the community and family members was received by 84.9% (141/166) of PTB patients. The summary of perspectives of PTB patients is as shown (refer to Table 1).

**Table 1: The Perspective of PTB Patients on Care**

	n	% (n/N)
Access to information on TB	137	82.5
Access to a diagnostic centre	132	79.5
Access to prescribed medication	138	83.1
Adequate nutrition	137	82.5
Social support from household contacts & community	141	84.9

N=166 (total number of PTB patients)

### Perspectives of HHCs of PTB patients

A majority of the HHCs at 86.6% (154/175) were able to access current information on PTB whenever they visited the hospital. Almost all HHCs at 92.0% (161/175) stated that their patients received counseling after diagnosis while a majority of the 82.9% (145/175) reported that their patients were able to obtain prescribed medication without any challenges. A majority of HHCs at 94.3% (165/175) stated that the PTB patients received social support from other household members. The summary of perspectives from HHCs is as shown (refer to Table 2).

**Table 2: Perspective of the HHCs of PTB patients**

	n	% (n/N)
Access to current information on TB	154	88.6
Availability of prescribed medication	145	82.9
Adequate resources for nutrition	153	87.4
TB patient counselled after diagnosis	161	92.0
Social support from household members	165	94.3

N=175 (total number of HHCs interviewed)

Additionally, the HHCs shared their experiences as caregivers to PTB patients during data collection that were recorded and transcribed. This was done through unstructured interviews. Some excerpts were reported verbatim from the recorded responses as follows:

“This disease has made me very lonely. Since my husband was diagnosed no one comes to visit and even my neighbors are not as welcoming as they used to be”. Respondent A

“I wonder if there is something wrong with my family. This is the third person in our family to get this disease. Perhaps there is something we are not aware of that is making us sick”. Respondent B

“I don’t have much money and worry a lot about how to keep my children safe. Should we use different utensils? We live in one room and it is impossible to open the window at night for

ventilation. Security is not so good where we live". Respondent C

"I am worried for my children. What if my husband does not make it? What if I also get sick? Who will take care of our children? People fear this disease". Respondent D

## Discussion

Household contact tracing of index PTB cases has been advocated as a key component of PTB prevention strategies for many years due to the higher cumulative exposure to *M. tuberculosis* through close physical contact and social interactions. The prolonged exposure predisposes HHCs to a higher risk of infection, morbidity, and mortality. The WHO recommends routine contact tracing and investigation in PTB high burden countries through counseling and education of HHCs, who are the primary caregivers for active PTB patients at home [3,4]. However, implementation of these recommendations in low-resource settings is poor hence screening of HHCs has remained sub-optimal.

An investigation of LTBI in this population reported a high prevalence among the HHCs, with the Interferon Gamma Release Assay results for over half (55.7%) of the participants indicating positivity for LTBI, which was higher than the global average of 23% [5]. A study in Ethiopia showed that individuals that lived with a PTB patient in the household had a three-fold increased risk of developing the infection [6]. Interestingly, almost all of the HHCs in our study did not have any knowledge of LTBI. There was a lot of anxiety noticed among majority of the HHCs in our study group when we relayed the results of a positive LTBI test result from the Interferon Gamma Release Assay. The HHCs who tested negative wanted to know how often they needed to test for LTBI while living with the PTB patient. Coincidentally many were also not aware of their HIV serostatus. As at the time of collecting this data, the country's national policy on LTBI testing and treatment considered HHCs who were HIV positive adults and children <5 years of age. These groups are at higher risk of developing full-blown tuberculosis disease on exposure due to poor immunity [7,8]. The recently launched Kenya Latent Tuberculosis Infection policy of 2020 by the Ministry of Health enhanced the scope of testing and treatment of LTBI to include all household contacts of known PTB patients. The policy allows for use of both Tuberculin Skin Test (TST) and Interferon-Gamma Release Assays (IGRAs). The proposed treatment options are based on WHO recommendations of 6-month isoniazid daily (6H) or 3-month rifapentine plus isoniazid weekly (3HP) or 3-month isoniazid plus rifampicin daily (3RH). In the Kenya policy document 6H is the preferred treatment option for anyone with a contraindication to the above two regimens [8].

In the study population majority of HHCs were satisfied with the health care resources that were available to their patients including diagnosis, counseling, and availability of prescribed medication. Many HHCs doubled up as providers of home-based care for the patient. As has been documented in other studies, depending on the severity of the illness, the PTB patient relies a lot on other members of the household for support in physical and psychological care [9]. In addition, most of the patients' families in informal settlements are confronted with extra social, financial, and clinical burdens associated with TB disease. Consequently, alleviation of poverty would reduce the risk of tuberculosis transmission and the risk of its progression from infection to disease [3].

The HHCs in our study discussed the challenges they faced living with and taking care of PTB patients and were classified as follows: Psychosocial challenges: HHCs had challenges dealing with

personal fears of caring for a patient infected with a disease considered in the community as 'dangerous'. Some faced stigma from other family members and neighbors. They noticed that visitors shunned their homes, limited social interaction or refused any food offer from the host. A study on the effects of stigma in Indonesia found that stigma affects both the TB patient as an individual and also the family and caregivers, a situation described as courtesy stigma [10]. These negative attitudes affected the mental well-being of the HHCs and negatively influenced the patients' self-esteem.

**Care-giver burnout:** Physical exhaustion dealing with the physical needs of the patients impacted the other members of the household, and most significantly the spouses of the patient and children. Mental exhaustion arose from anxiety about the patient's progress, the likelihood of getting infected, and the need to constantly encourage a PTB patient battling low self-esteem. They also had concerns about dwindling resources due to diminished family income arising from job losses in cases of sick spouse(s). Majority of the study participants did not have private medical health insurance covers and relied on daily wages as casual laborers.

**Hygiene needs:** Most participants lived with the PTB patient in a one or two room house that had minimal ventilation. Some HHCs observed that TB patients were isolated from the other patients while in the hospital and wondered how they should minimize the spread of infection at home where available space could not allow for any isolation. Water for domestic use was inadequate in most households and this was a major hurdle when bathing very sick patients especially in communal facilities. Washing the patients' clothes/bedding that were sometimes visibly soiled and cleaning of utensils used was mainly done using soap because disinfectants were costly. Waste management practices differ considerably between formal and informal households where collection of waste, if any, remain irregular and random. In some instances, generated household waste ended up in the environment around the house or by the walkways and roadsides. All the household waste, including what would be categorized as clinical waste such as vomit, sputum, pus, tissue paper, soiled linen was disposed off like any other normal waste.

## Conclusion

While most of our study participants acknowledged adequate accessibility to PTB diagnosis and treatment services offered in public facilities, several gaps in home based care persisted from which the following recommendations were drawn:

- i. Sensitization on available testing and treatment of LTBI for all HHCs of PTB patients;
- ii. Psychological care through individual and group counseling of PTB patients, their HHCs, and caregivers;
- iii. Training of HHCs on home-based care with the focus on minimizing exposure and risk of infection from the index case, reduction of air pollution in the home and safe handling of clinical waste;
- iv. Adoption of a PTB HHC Card Notification system by health facilities handling TB patients; and
- v. Further research on the effectiveness of the PTB HHC card notification system for those in contact with PTB patients at the household level.

## Ethical Considerations

The data was extracted from a larger study on "The role of Human Leukocyte Antigens and *M. tuberculosis* strain variation in susceptibility to infection among pulmonary tuberculosis

patients and their household contacts in Kenya". The Kenyatta National Hospital/the University of Nairobi Ethics and Research Committee (KNH/UoN ERC) reviewed and approved the study, Reference No. KNH-ERC/A/392. Permission to conduct the study was obtained from Mbagathi County Hospital, Nairobi, Kenya.

### Competing Interests

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

### Authors' Contributions

Susan Odera, Julius Oyugi, Omu Anzala and Marianne Mureithi participated in the development of the study proposal, recruitment of study participants, processing of clinical specimen, data entry and analysis, and manuscript writing. Angeline Kirui, Andrew Aballa, Noel Onyango and Idah Ombura conducted data analysis and critically reviewed the manuscript. Comfort Ananda and Meshack Obwogi participated in collection and review of sociodemographic data and manuscript writing. All the authors approved the final version to be published.

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