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Research Article

Situations and Expectations of TB Care Continuity for Post-Release Persons in Jakarta, Indonesia: A Descriptive Phenomenology

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Abstract

Post-release tuberculosis (TB) treatment completion is crucial for TB prevention and control. However, the situation of post-release continuity of TB care is uncertain. The study aims to describe the situation and expectations of TB care continuity for persons after release from a prison in Indonesia using descriptive phenomenology. The participants consisted of seven TB patients, a nurse, a physician, a treatment observer in the prison, and a representative of an NGO. All participants were purposively recruited. The TB prisoner-patients were chosen based on having TB and the providers were selected based on the criterion of having experience in caring for prisoners with TB who had to continue their treatments after release. In-depth semi-structured interviews were conducted to explore the perspectives of the participants in post-released continuity of TB care situations and their expectations. The interviews were digitally recorded, transcribed verbatim, and analyzed using Colaizzi's phenomenological method.

Five themes emerged: (1) lack of employing any provider guidelines to enhance post-release TB continuity of care; (2) loss of contact with patients at the point of release; (3) rarely receiving reports back from the health centers due to failure in patient follow-up; (4) desire to recover from TB and looking forward to healthty living after release; and (5) expecting providers to supervise the medications in the pre- and post-release period. This study recommends mechanisms to ensure post-release TB treatment continuation to prevent disease progression and transmission into the community.

Keywords: post-release, prisoner, treatment completion, tuberculosis

Introduction

Tuberculosis (TB) is a worldwide burden for many countries. Some progress was accomplished in the Millennium Development Goals target achievements in 2015 and in the indicator to reduce TB prevalence by 50% compared with the baseline of 1990. Additionally, decreasing the mortality rate by 50% compared with the baseline was nearly realized (47%). However, there were several challenges in global TB control in 2014, including approximately 9.6 million people who were newly infected with TB. Thirty-seven percent of cases were unidentified in one year, and around 480,000 people were diagnosed with advanced multidrug-resistant TB (MDR-TB). In conjunction with human immunodeficiency virus (HIV), TB is the main cause of death.[1]

The burden of TB in a country is closely related to TB prevention and control in a correctional facility affecting both inmates and the community, particularly in countries with inadequate national TB programs and high imprisonment rates. TB is also the main health problem in correctional facilities with incidence rates that range from 4 to 81 times higher than the general population. The risk of TB in this setting is associated with poor ventilation, lack of sunshine, overcrowding over long periods of time, an increased number of HIV infections and obstructive airway diseases, fast development of latent tuberculosis infection, intravenous drug use, inadequate nutrition, and unhealthy behaviour (e.g., smoking and alcoholism). These conditions are compounded with the development and transmission of drug-resistant TB. Determinants of MDR-TB progression and transmission include overpopulation, delayed case detection, lack of contact screening, poor infectious disease treatment, elevated inmate turnover, inadequate TB infection control protocol, and the limitation of healthcare service accessibility that inhibits the control of TB in this setting.[2-4]

Continuity of TB care is crucial for those persons released from correctional facilities.[3] TB incidence in this setting is interconnected with the community since correctional facilities are believed to be TB reservoirs.[5] They transmit the disease within the setting through inmates, staff and visitors, and it spreads to the general community through prison staff and also released inmates who need to finish their treatment after release. This situation occurs in MDR-TB cases as well and plays a main role in hampering TB control indicator achievements in the overall population[3,4] Continuity of TB care after release has become a big concern due to several factors. These include the lack of enthusiasm to consider public health improvement because it is the responsibility of the penitentiary, inadequate integration and communication between civilian and correctional TB services in providing continuing care for released inmates, and uncertain roles of dissimilar ministries and health authorities.[2,6]

Indonesia was one of the highlighted countries in global TB reports in 2015. It ranked second in the largest number of TB cases. The TB incidence was double and the burden was greater than the previous prediction.[1] In correctional settings, TB is ranked the fourth highest in the number of cases and has become the second most common cause of mortality among inmates.[7] Besides West Java Province, the highest number of TB cases was found in Jakarta prisons and jails whereas there were 207 active TB cases in 2014.[8]

The continuity of post-release care also becomes an issue in this area influencing TB treatment completion after release from prisons and jails. From a preliminary study in Jakarta Province, the transfer rate in this setting reached 81.3% in 2014 and decreased to 76.3% in 2015. The lower transfer rate in 2015 included those who were transferred to other correctional facilities as well as into the communities. This data also explains the increased

rates of lost to follow-up cases from 19.7% to 23.7% in 2014 and 2015, respectively. According to the national TB control guidelines, it should not be more than 10%.[7]

The situation of TB care continuity for the prisoners after release seems to be unclear. It is imperative to explore the current situation and expectations of post-release continuity of TB care from the perspective of prisoners and providers. This study is important to evaluate the national TB control guidelines to enhance the post-release TB treatment completion of the inmates. This present study aims to describe the situations and expectations of post-release continuity of TB care in Jakarta, Indonesia.

Methods

Design

A descriptive phenomenology design was employed to study and comprehend individual experiences to capture the 'essential' component of the occurrence.[9] The study was guided by the research question: What are the situations and expectations of post-release continuity of TB care and the roles of nurses in supporting this? It was a part of a participatory action research, particularly in the reconnaissance phase that aims to explore other people or group experiences engaged in and influenced by a practice.[10]

Participants

Eleven people participated in the research that included seven people with TB, a nurse, a physician, a treatment observer in the prison, and a member of an NGO who were purposively recruited. The prisoners with TB were chosen based on the criteria of having TB and must continue their therapy after being released, no mental illness, be able to express their opinion, and agreed to voluntarily participate in the study. The researcher identified the participants by asking the nurse to identify potential participants of all TB patients meeting the criteria. In addition, the providers were selected based on the criterion of having the experience of caring for inmates with TB who had to continue their treatment after release. Saturation was achieved when there were no available participants to get additional new information in the setting.[9]

Setting

The study was conducted in Jakarta, Indonesia at a prison that accommodates approximately 3,000 prisoners even though its design capacity is 1,085 prisoners. The prison clinic provided therapy using the Directly Observed Treatment Short Course with regular supervision from the provincial Office of Ministry of Law and Human Rights. The TB program in this service was started with TB active and passive screenings, diagnosis, treatment, and referral to other institutions including other correctional facilities, hospitals or primary healthcare (PHC) services. The referral process of TB patients was adequate among institutions under the Indonesian Ministry of Human Rights. However, the providers never directly referred and followed up the patients to services under the Health Department in the national, provincial, and city levels. After the referral process, patient care becomes the responsibility of nurses in the referral services.

The TB care providers in this setting included a physician as a TB-HIV program manager, a physician as a TB program coordinator, and a nurse for documentation and reporting functions in the TB program. Two additional nurses were involved in the program. They were trained in conducting sputum smears for laboratory testing; however, their role seemed unclear. In addition, two associate prisoners trained in TB sputum smear facilitated the program in smear preparation and anti-TB drug distribution to the patients. The TB program in the prison was also supported by NGO personnel in ensuring pre- and post-release treatment completion, and referring released prisoners with TB to community healthcare

services, namely primary healthcare centers and hospitals. They also reported the follow-up results from the referral healthcare services to the prison.

Ethical considerations

The researcher attained approval from the Institutional Review Board, Faculty of Nursing, Prince of Songkla University (Reference number 0521.1.05/925), and from the Jakarta Provincial Office of Indonesian Ministry of Law and Human Rights. The study was explained to all participants who would remain anonymous and provide written informed consent. They could voluntarily engage in this study and withdraw anytime they wanted. When the participants agreed to be involved, they were asked to sign a written informed consent form.

Data collection

Data collection was performed from March to November 2015. Semi-structured interviews were conducted with the providers regarding demographic data of the participants. They were also asked questions regarding their experience in caring for prisoners who continued their TB therapy after release, post-release TB therapy results, and their efforts to encourage patients to finish their TB therapy after release. A similar method was used in collecting data from prisoners including their experiences, expectations, and planning to complete their TB treatment after release. All recorded data were transformed into transcripts for analysis.

Data analysis

Data were analyzed using Colaizzi's method which included these steps: (1) reading the transcripts repeatedly to obtain an impression of the overall content; (2) extracting meaningful statements and coding based on descriptor, page, and line numbers in different sheets; (3) formulating meaning from the highlighted statements; (4) categorizing them; (5) describing all emerged themes into comprehensive descriptions; (6) eradicating the unnecessary, mis-represented or overemphasized descriptions; and (7) validating the findings of the participants by returning the transcripts to the participants for their confirmation.[12]

Trustworthiness of data

The researchers employed strategies to ensure the trustworthiness of the data. Prolonged engagements, participant and method triangulations, and audit trails to track findings from raw data were used to enhance credibility. Participant confirmation and member checking were done to increase confirmability. Transferability was maintained by providing thick descriptions regarding study context, the community situation, participants, and setting environment. Finally, dependability was performed by attaching samples of sentences from the sources of the data.

Results

The emerged themes consisted of: (1) lack of employing any provider guidelines to enhance post-release TB continuity of care; (2) losing contact with patients at the point of release; (3) rarely receiving reports back from the healthcare centers due to failure in patient follow-up; (4) desire to recover from TB and looking forward to healthty living after release; and (5) expecting providers to supervise the medication in the pre- and post-release period.

Lack of employing any provider guidelines to enhance post-release TB continuity of care

The physician and the nurse claimed they did not have any detailed guidelines for the pre- and post-release periods for TB patients who should continue their treatment after being released to facilitate the treatment completion. They compared the TB program with the HIV program which has clear mechanisms. The physician stated:

> *"Regarding the pre-release, it is not detailed like the HIV program. So, anybody can do it. It could be me or N_1. So, even now, it has not been thought through."* (D_1)

The correctional nurse described an experience of ineffective guideline implementation, particularly in TB medicine logistic management. Ideally, one box of the medication should be provided for one patient. However, in the execution of providing medication, the drug observers distributed one package for all patients and the nurse did not supervise it.

> *"…. until yesterday, I really felt that I do not really monitor the situation well. One time I asked, 'Where are the drugs? Are they finished?' I learned that instead of giving a single box of medications to one patient, the medications were distributed to many patients. Recently I reorganized everything (pointing to the lower part of a drug cupboard)."* (N_1)

In the post-release period, the healthcare providers in correctional facilities also mentioned that they do not have a detailed program compared with the HIV program which includes parole board involvement. The providers have tried to involve the parole boards. However, the mechanism was still not clear.

> *"... it is not specified for TB, compared to HIV, and working collaboratively with the Parole Board... We've never dealt with the mechanism yet because we were still in a meeting in our office at that time... At that moment, Parole X (mentioning a parole institution) asked about the process for the patient in order to continue his treatment. The parolee's enthusiasm is good. But, how about the mechanism? What kind of record?"* (D_1)

Losing contact with patients at the point of release

There are two types of release, namely release on the expiry date and release on license. The first category includes those who finish the whole length of sentence and the second one is for those who are released before their expiry date and serve the remaining punishment period in the community. Lost patients occured in both types in which some prisoners recognized their release date and the remaining prisoners did not know about it. The physician complained that the patients were suddenly released before being prepared to be referred. She said:

> *"That's the problem. Some persons knew the time they would be released. 'Your decree has been published'. However, some prisoners were suddenly released. So, some prisoners know their date of release based on decree and some of them don't, ..."* (D_1)

The providers realized the situation when treatment-observers could not find the patients in their cells as described by the physician:

> *"We just realized that the inmate was not there for his medication. The drug-observer said, 'Ma'am, X did not take his drug.' 'Why?' When we looked in his cell, 'Oh, he was released.'"* (D_1)

The nurse counted the number of lost patients after release because they did not report when knowing their release date and the provider did not acknowledge it. She explained:

> *"There were two or three persons lost this month because we didn't know, the decree had not been published yet, suddenly today it was published, so they didn't report. Those who were released on an expired sentence, their decree were directly published and they didn't report as well. Three have been lost. January to February around two or three, right? Mr. Sy... (Trying to count the number). Last time Mr. Sy. Oh No... From December, there are three."* (N_1)

Rarely receiving reports back from the healthcare centers due to failure in patient follow-up

Furthermore, the provider rarely received reports back from the healthcare center. There are two types of feedback from the referral services which must be reported back to the correctional facility; they include responses stating that the patients visited the services (TB09 form) and the final treatment results (TB10 form). Generally, the healthcare providers in the prison do not receive those documents. The nurse conveyed:

> *"The patient didn't report. The point is we didn't receive the TB09 feedback…. The TB10 was never been returned from the PHC."* (N_1)

It was confirmed by the NGO personel stating:

> *"... TB10 must be returned to the service, but in fact it wasn't."* (O_1)

Several situations were associated with this condition. There was no information regarding patient follow-ups since they were predicted to not visit the referral services. The nurse and the NGO personnel mentioned:

> *"Most do not go back because if the prisoner is now a civilian, he is not a prisoner, so he does not feel like going back to the PHC."* (N_1)

> *"Usually, but not all PHCs receive the TB09 form. Most of the released prisoners rarely report to the nearest PHC."* (N_1)

> *"I am most resentful when we had an appointment (in the referral PHC) and, they didn't come. I have to be patient."* (O_1)

Also, the patient did not continue visiting health services in the post-release period due to the use of illlicit drugs. The nurse narrated:

> *"His mom went to the PHC. She told them that he used alternative medicine: Better, healthier, and died. When searching for information, in fact, he started using opiates again and he stopped his therapies."* (N_1)

A patient predicted this condition as well by conveying:

> *"If he's using illicit drugs again, perhaps he doesn't feel like taking the medicine."* (P_6)

Additionally, re-arrest was a reason why the TB patient did not come to the referral service. The NGO person got a report from a nurse in a referral service as follows:

> *"... Thirdly, he was re-arrested.. for example, if there was a prisoner who was arrested, I asked for confirmation. Just like a case in a PHC, he was HIV only, no TB. But when he was arrested, the nurse in the PHC contacted me directly because that person was re-arrested."* (O_1)

In other situations, TB patient follow-ups failed due to invalid addresses and phone numbers of the patients and their families. The nurse and the NGO personnel complained about similar situations.

> *"For most patients who would be released, their addresses were not valid. It isn't a fixed address because usually they rent a house. They said this was their address, but after release they never returned to the address. Most are like that, false address."* (N_1)

> *"At that time, there was an MDR-TB patient. For the patients from outside this province, such as City Y, W, Z, administratively he was a patient of this prison. However, he*

was located in Hospital X. When he would be released, we coordinated with Local Health Departments of city X and Y, and a PHC in City Y, and Parole Y; so many parties. However, finally the patient was lost. First, it was because of the address. So, the patient had moved." (D_1)

"Usually, if they had discontinued like that, I never followed up based on the address, because from my experience, I was tricked with an invalid address. The number was valid, but the RT and RW (sub district numbers) were invalid. The last time when I went to the field, I was shocked because it was a luxurious house. Actually, he was a poor person. It means that the prisoner didn't want to be traced." (O_1)

The NGO person also shared her experience in following up patients by phone and found that it was an invalid number. Sometimes, it could be connected when the patients were still in prison. However, it could not be connected after they were released. She said:

"For example, we borrowed a nurse's mobile phone, when he was in prison (mentioning another prison institution). I called. It could (connect).... He couldn't lie. He must provide it. But, after being released, it's cut. If not, it's turned off. Perhaps, it's his mother's phone or whatever. I don't know. It's not connected. The point is, it is not connected. Sometimes... toolaaleeet.... toolaaleet.... Dis-connected...." (O_1)

The limited response from referral services was associated with the lack of communication between the providers in the prison and in the community. The nurse mentioned:

"We never got any response or feedback from the PHCs and the related institutions never provided the feedback to us." (N_1)

"We never directly referred to the PHC, we reported to the supervisor." (N_1)

The physician mentioned:

"The feedback is on the TB10 format, isn't it? Maybe from the PHC itself, I also never asked why they didn't give feedback yet. I also forgot to ask them because mainly they finished their treatment in the prison." (D_1)

Desire to recover from TB and looking forward to healthty living after release

All patients have a desire to recover from the disease, be healthy, and not spread the disease.

"At least I'll be healed. I can be cured. My expectation is that I can be healed, and have a healthy body." (P_1)

"I want to recover" (P_2)

"The point is I don't want to spread the disease to my family. Let it be only me who is treated." (P_7)

The same expectation was expressed by the physician:

"... keep preventing to spread risk to others. Live healthy, so it doesn't develop to be more severe, such as category II or MDR-TB..." (D_1)

All prisoner-participants expected to complete TB treatment by continuing the therapy after their release from the prison.

"I will continue until completion." (P_2)

"I plan to continue my medication near my home, Ma'am. I will ask for a referral letter

from here, I will continue at home…. If Allah wills it, it will be completed, Ma'am." (P_3)

"Just finishing this therapy; the point is until the disease is gone." (P_5)

The providers in the prison also had similar expectations. The nurse and the physician expected the patients to continue consuming the anti-TB drugs after release.

"The patients routinely consume the drug." (N_1)

"We expect that will be continued outside." (D_1)

Expecting providers to supervise the medication in the pre- and post-release period

The patients expressed their expectations regarding the nurse's roles in ensuring the treatment completion. Some patients expected the providers to directly monitor their health and treatment from the pre-release period.

"I expect to be supervised every day and asked about my condition..." (P_6)

"Right, asking about our condition." (P_7)

The NGO person expected the physician to take responsibility to supervise post-release TB treatment completion. She said:

"That is the responsibility of the physician when providing medication. The responsibility is a strategy that is there for the prisoners in order to continue their therapy outside…. I said it like that but it's supervised. Whatever, the physician has to know." (O_1)

She also revealed a recommendation to maintain communication among the providers in the prison, the NGOs, and those in the community to ensure patient TB treatment completion.

"The point is networking, which is communication because if there is no communication, it must be no…. For example, I refer and there is communication and the prisoner discontinues his therapy, she must contact me because I will pursue him, so that I don't lose contact." (O_1)

This was in accordance with the nurse's expectation to have collaboration with the NGO in the follow-up of patients in the post-release period by stating:

"My expectation is we can manage these released patients with the institute (NGO). Do they consume the medicines or not? Finished or not? There is a follow-up for the released patients…" (N_1)

Discussion

The Indonesian government has published a guideline for TB control in correctional facilities including how to ensure TB treatment completion after release. It involves pre-release activities, transfer, and patient follow-up in the community and the role of each party. The national TB program guidelines outline the pre-release TB activity which has an information provision about TB treatment and services to continue treatment for prisoners for at least three months before release. The post-release TB program is information searching by correctional providers/NGO regarding TB therapy continuation of released prisoners. The guidelines also explain the detailed action from release date identification, to referral, and follow-up and the role of each related party.[7]

The participants mentioned that they did not have any detailed procedures for post-release care in the prison even though there is a published guideline with the detailed action mentioned before. This situation reflected that the healthcare providers

in the prison inadequately implemented the national TB guidelines for correctional facilities which was possibly caused by several conditions. Most healthcare services in correctional institutions are organized by other Ministries of Health such as the Ministry of Justice with barriers of professional quality control and establishing linkage with civilian services due to separation from general healthcare services.[13] Either inadequate TB management in the correctional facilities or post-release follow-up could challenge TB control in the community.[14] Program barriers may include an unclear project framework, undetermined personnel responsibilities and functions, indefinite procedures, and a lack of political will. These require collaboration of both the public health and corrections agencies by sharing roles and resources to address healthcare service gaps for prisoners.[15]

Lost patients on release could be linked with the limited coordination between the jail and probation departments in identifying released inmates who should contact the service and ensure their understanding of their conditional release into the community and the monitoring.[16] There should be an administrative system for unplanned release of prisoners who are undergoing TB treatment.[15] Discharge planning should be performed at the time of the patient's diagnosis. Each client needs to have a case manager or a team of case managers (i.e. jail staff, community health care staff or dually based healthcare workers who work in both settings) to work with the prisoners in the prison or society to address the patient's needs. On release, the case managers should have a specific appointment with the former prisoners including the date, time, and address.[15-18]

There was no feedback from referral services regarding TB care continuity after prison release due to several barriers including loss of contact with the patients on the date of their release, incorrect post-release information, re-arrest, illicit drug use, and a limited referral process. Inmates may provide invalid contact information and aliases because they fear incrimination or relocation by the authorities. (11) The situation of lost patients on release has been described previously.

Relapse into illicit drug use and recidivism lead to the interruption of care. Both are associated with psychological conditions such as isolation, hopelessness, and financial problems, such as the inability to afford housing and unemployment.[19,20] Additionally, illicit drug use relapse occurs because ex-users return to their previous environment which stimulants use of alcohol and finally they fall back into illicit drug use.[21] Finally, the linkage between correctional facilities and the community health services is another concern to ensure continuity of care. [13,15,20] Usually, collaboration with community services involves HIV patients.(15) This situation also occurs in Indonesia, as mentioned by healthcare providers in the prison.

Most TB patients expected providers to supervise the medication in the pre- and post-release period. This expectation reflected caring performances of the providers, particularly the nurses. A previous study claimed that correctional nurses have a problem performing caring behaviors due to dilemmatic situations because the imprisonment system influences the nurse-prisoner relationship. Nursing provides a caring atmosphere while incarceration works on the forensic view. In addition, some existing policies prevent the nurses from engagement in particular caring behaviors such as touching, hugging, and self-disclosure.[20] In this challenging situation, the nurse should find a strategy to care for their prisoner clients.[21]

All participants mentioned their positive intentions to complete the treatment after their release. These positive intentions are relevant to the patient's positive expectation in regaining good health after release and they significantly recognized their health needs.[20,24] This leads to optimism that they

will take responsibility in fulfilling this requirement during the post-release period.[16] The realization was still influenced by those barriers in visiting the referral services that lead to no feedback from the referral service in the community. Furthermore, the post-release health-related experiences may vary depending on the variety of characteristics and backgrounds of the ex-offenders.[25]

A limitation of the study is the selection of the participants. The researchers did not involve healthcare staff in the community services and family members that could capture additional phenomenon in the community setting. Moreover, the study did not reveal the perceptions of the patients that could influence TB treatment continuity after release.

Conclusion

Three themes arose regarding the situation of post-release continuity of TB care: (1) lack of employing any provider guidelines to enhance post-release TB continuity of care; (2) losing contact with patients at the point of release; and (3) rarely receiving reports back from the healthcare center due to failure in patient follow-up. Furthermore, two themes emerged concerning the expectations of the participants. All participants had the desire to recover from TB and looked forward to healthty living after release. They also expected providers to supervise the medication in the pre- and post-release period. The study recommends establishing administrative procedures to identify the release dates of the TB patients, balance the nurse-prisoner relationship, and establish adequate communication between the healthcare services in correctional facilities and in the community to ensure post-release TB treatment completion. Moreover, the nurse should involve all related parties in the release of patients and establish a plan at the time of TB diagnosis for those who have to continue their treatment soon after their release.

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