

Children and Home-based Care for TB patients in Chiang Mai, Thailand


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Introduction

- ❑ Tuberculosis (TB) is an infectious disease that is a public health problem in developing countries
- ❑ Thailand in 2007, was ranked 17th globally for the prevalence of TB
- ❑ One of the solutions to prevent drug resistant TB is a program to ensure that patients will get through the whole TB treatment course; this is known as the **Directly Observed Treatment (DOT)**, which is **Home-base Care (HBC)** where the family becomes the main factor to influence the achievement of the TB treatment.

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- ❑ The family structure and relationships among members, roles and responsibilities have changed. When adults go out to work, children take the role of caregiver to provide care to guardians or parents with TB
 - ❑ Children who live with and have direct interaction with TB patients are vulnerable to infection with TB. Moreover, children may face health and social problems such as care taking, and being discriminated against by friends or neighbours because they are labelled as TB carriers
 - ❑ Children face many problems such as more responsibilities, and being discriminated against by friends or neighbours because they are labelled as TB carriers



Objectives

- ❑ To explore the lived experiences of children who live with TB parents or guardians
- ❑ To explore the roles in the family they take to get involved in TB treatment of their parent or guardians
- ❑ To explore the affects to their health and life

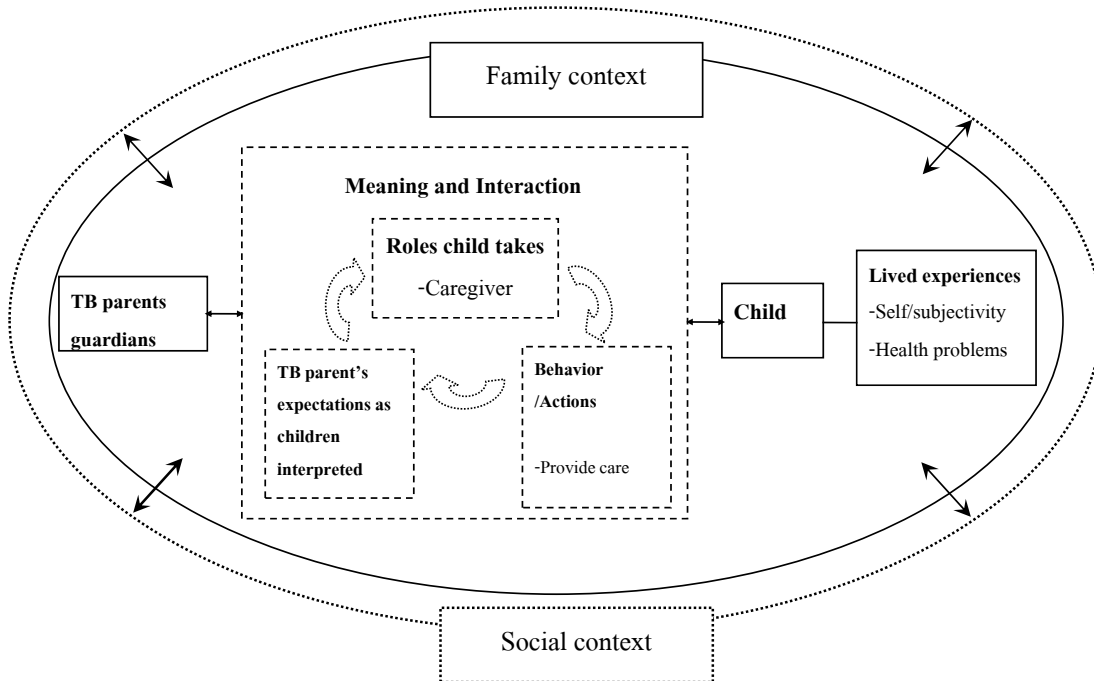
Methods and Design

- This is a qualitative research using multi methods
 - Participatory and non-participatory observation
 - Narrative interviews and semi-structured interviews
 - Primary and secondary data collection
- Informants are 8 children aged 12-17 years old
- Key informants include
 - 8 cases of TB parents or guardians
 - 3 health providers

Conceptual Framework

- This research employed Symbolic interactionism as a perspective to explore the interaction between children and their TB parents or guardians, under family and social contexts
- The family context refers to the structure of the family, size, education, and economics of the family, and their experiences with TB.
- The social context is regarded as children's roles and the expectation about children in the community, the meaning of TB and care.
- While children are living with their TB parents or guardians in the same house, they share space, life and time together. Their interaction affects the child's health and life.

Conceptual Framework



Source: Developed in association with thesis advisors.

FINDINGS

The following table shows background information in order to understand the children's' contexts.

Table 1: Background Information of Informants

Informant	Sex	Age	Education (Grade)	Number of family members	TB patient (Relationship)
Ann	F	15	10	5	Grandfather
Bird	F	12	7	4	Mother
Cocoa	M	14	9	3	Grandfather
Dear	F	15	9	7	Grandfather
Ed	M	12	7	4	Father
Film	M	12	7	9	Grandfather
Good	M	14	10	4	Grandfather
High	F	12	7	4	Father

Family & Social Contexts

- ❑ 4 informants are being raised by grandparents in extended families
 - compensated care (เลี้ยงส้าย) by grandparent
 - informants are expected to have less responsibility about providing care for TB patients
- ❑ 4 informants are being raised by parents in nuclear families
 - adults are busy earning a living and taking care of the home
 - informants are expected to have more responsibility providing care to TB patients or support adults to provide care.

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- ❑ Most parents and guardians of the informants had low levels of education, thus they support their children to get higher education
 - ❑ Most of the families are farmers or laborers. Four of the eight families' incomes come from only the family leader, who is father or mother
 - ❑ Most respondents live with their family. Children have a closer relationship with the person who takes care of them.
 - ❑ TB remains stigmatized in the communities: villages, schools and market

Lived experience of children

- Children perceived the meaning of TB differently depending on their family's attitude toward it.
 - Families focused on stigma which causes children to perceive they are TB carrier, causes them have less self esteem to attend social activities and isolate or hide themselves at home.
 - Families understand that TB is a curable disease so they focus on the patient's need to have discipline to complete the treatment. Children pay more attention to taking medicine and taking rest and they support their guardians and parents to do so.

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- Children more aware of TB when they experience it
 - 4 informants caught TB from their parents or guardians. Children experienced TB treatment themselves. They give the meaning to TB is curable disease. However, they are scared of TB because of the long time for the treatment.
 - 4 informants have not got TB, they have learnt about TB via their TB parents or guardians. They are less aware of TB if their guardians are not having severe symptoms or weakness. Therefore, TB is less meaningful and less affect on their health and life, compared with the previous group.

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- All informants provide care to TB guardians
 - Children provide personal assistance to TB patients
 - An example is Ed, he feeds father and helps him about toileting during his father stay in a hospital for TB treatment
 - Children provide emotional support or are a supporter to TB patients
 - For example, Bird obeys mother to not play with other kids and keep TB story secret. She started to do the housework and take care of herself because her mother avoids interacting with and providing services to all family members, to prevent the spread of TB.

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- The family and social context that emphasizes gratitude, and a compensated care still exists in Northern Thai society.

Together with the close relationship between guardians and children, this influences children to provide care in order to repay to grandparent, and be a grateful child.

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- In the small family that there are few members, if the leader is sick with (or dies from) TB, it causes many problems for the family : domestic economics, amount or responsibilities of each person, children's education, etc.

Children realize of the important of parents, their love and care towards children. This influences them to pay more attention about treatment and express love and care to their parents or guardians.

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- In the nuclear family children have to be a carer while adults are busy with earning. Children feel more comfortable and gain more confidence to provide care, because they've done it when their guardian was sick with TB.

- An example is Ed, he said,

“It is sure, I am able to provide care to anyone who is sick in the family, because I used to do it when my father was sick”

DISCUSSION

- In principle, adult-children are able to provide good care to their parents the same as adult. However, sometimes they are not able to be caregivers because they do not have the opportunity to take that role.

- For example, Good wants to support the family but his grandparent want him to focus on study.

“I love them, I want to support them, but I am too young ... I have not things to do in home ... they want me to focus on my study ...” Good, 14 years old boy said.

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- The interaction between TB guardians and children, influences children’s habits & subjectivity

- Guardians who express their love to the children, motivate children to repay them by providing care and support.
- Children who know they are the inner strength of their guardians, to encourage patients to complete the treatment and not feel lonely. They are willing to provide care or emotional support to TB guardians.
- Guardians who have no time or less communication with children cause children to not know what adult expect from them, and what they are supposed to do.

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- Negative consequences such as stigmatization and guilt can also be turned into motivation to being cured of TB.
 - Children and adults who feel self-stigma and fear being discriminated against by others try to complete the treatment course, to get out of the TB world.
 - Adults who feel guilt about spreading TB to their children try to complete the treatment course and encourage children to do so. This helps them decrease guilt.

Conclusion

- The background of the family is the important factor to determine children's roles in the family; size of family, education, income, division of duties and the relationship among members in the family.
 - Size of family: children in a small family have more chance to be assigned to provide support and care to TB guardians.

An example is Ed, he provided care to father while mother took care of home and work.

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- Education: children in poorly educated family are encouraged to focus on study more than the housework or provide care.

An example is Good, his grandfather wants him to focus on studying, it is only a goal for him.

- Division of duties: children may take on easier duties while adults take more difficult duties.


For example Bird, takes care of easier housework such as fill water bottles, cooking and take care of herself, while her TB mother does more difficult duties such as laundry and farming.

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- Income: children in low income family have to be a carer while adults go out to work.

An example is Ann, she does the housework and provides care while her parent go out to work.

- Relationship among members in the family motivates children to provide care. If children are raised by grandparents, and they have a good relationship they are willing to repay grandparent with care and support.

An example is Dear, she willing to work hard in order to support her grandfather, so he has more time to rest.

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- If what patients need is more than medicine, family is crucial for TB treatment. Love and care are the best medicines to cure the illness.

“... what she (Bird) does for me, what she says to me, it shows she loves me and this is the best medicines for me ...” Mother of Bird narrated.

Thank you