Enfermería Clínica 32 (2022) S58–S61

Enfermería Clínica

www.elsevier.es/enfermeriaclinica

The patient with multi-drug resistant – Pulmonary tuberculosis adherence to treatment: A qualitative study☆

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Received 26 September 2021; accepted 26 March 2022

KEYWORDS
MDR TB;
Qualitative;
Experience

Abstract
Background: Patients with multi-drug resistance tuberculosis might experience differently during the treatment than those without tuberculosis. This study aims to explore the experience of multi-drug resistance tuberculosis patients during the treatment period.
Methods: Six patients undergoing multi-drug resistance tuberculosis treatment were recruited as participants. This qualitative-phenomenological study uses an in-depth interview method and is completed with field notes. Data were analyzed using steps according to Colaizzi.
Result: The study identified five themes related to the patients' experience and behavior for the therapy, including the patient perceptions about the illness, perceived obstacles, factors that support adherence in treatment, hopes to achieve healing, and health promotion behavior.
Discussion: Many factors influence long-term treatment adherence. It is recommended to support patients with MDR TB who have been in care for a long time; policymakers and health practices must respect that condition of MDR-TB affects the psychosocial life of sufferers. Develop strategies to reduce perceived effects by providing opportunities to share their anxieties, suffering, and biopsychosocial changes.

Introduction

Multi-drug resistance tuberculosis (MDR-TB) is one of the major global public health problems that prevent the achievement of tuberculosis (TB) control in low and middle-income countries in the.[1] MDR TB causes not only high rates of morbidity and mortality but also increases psychosocial challenges in sufferers.[2]

☆ Peer-review under responsibility of the scientific committee of the 3rd Aceh International Nursing Conference (AINC). Full-text and the content of it is under responsibility of authors of the article.

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https://doi.org/10.1016/j.enfcli.2022.03.019
1130-8621/

Table 1 Demographic profile of the participants.

Participant	Age	Sex	Marital Status	Education	Job	Treatment Duration
P1	44	Female	Single	Senior High School	Entrepreneur	Two months
P2	46	Female	Single	Senior High School	Entrepreneur	Two months
P3	29	Female	Single	Diploma in Midwifery	Midwife	23 months
P4	57	Female	Married	Senior High School	Housewife	Nine months
P5	50	Female	Married	Junior high school	Housewife	Three months
P6	63	Female	Married	Junior high school	Housewife	Ten months

Based on data on May 17, 2018, the number of new TB cases in Indonesia was 420,994 in 2017.[3] The increasing number of MDR-TB cases in Indonesia causes the government to bear increasingly high costs for managing and controlling MDR-TB cases.[4] Besides requiring expensive medical costs and a long time, patients with MDR TB experience higher mortality than those infected with drug-sensitive TB.[5] From the results of a qualitative study examined in Pakistan, it was found that the burden of treatment costs was one of the most prominent factors besides drug side effects and trust, which was a failure in TB treatment.[6] Failure in treatment due to patient non-compliance in the treatment process can lead to tuberculosis germ resistance to TB drugs.[7]

People who experience recurrent disease or are resistant to various types of drugs need an extended treatment program.[8] The duration of standard treatment with Multidrug-Resistant Tuberculosis (MDR-TB) patients is 19–24 months.

Changes in medication adherence and behavioral practices in promoting self-care in pulmonary TB patients are urgently needed. Nearly two-thirds of the patients treated for TB are not aware of how TB is spread, so it is unlikely that the patient or family is aware of steps to prevent the spread of TB.[9] Therefore, getting an education about how TB is transmitted and adopting healthy behaviors can prevent the transmission of this disease to other people.[10]

Change in attitude and behavior in medication adherence is fundamental in promoting self-care in pulmonary TB patients. In 1987, Pender developed the theory of the Health Promotion Model (HPM). According to Pender's view, health-promoting behavior can be operationalized in life on an individual lifestyle. Pender develops HPM as a framework for describing health behaviors that focus on personal progress towards favorable circumstances and health improvement.[10]

The experience of MDR-TB in Indonesia has not been well explored. Therefore, this study aims to examine the experience of patients with MDR TB living in the area of the Lhokseumawe district of Indonesia.

Methods

This qualitative study with a phenomenological approach involved All patients with MDR-TB (6 persons) living in the district of Lhokseumawe, Indonesia, were invited to the study. They were recruited through their local TB program holders. Researchers collected data on the participants until saturation was achieved. Researches consider the data saturation has reached when many themes recur and no new themes emerge. Data collection utilized an in-depth interview method and field notes. In the interview, researchers used an open-ended approach to explain their experiences during the treatment period entirely. The data collection process was carried out from August to October 2019.

After obtaining approval for a research permit from the Nursing Research Ethics Committee of the Faculty of Nursing at Syiah Kuala University with research code number 112007160719, the researchers applied ethical principles to prevent ethical problems. Participants who agreed to participate in the study then signed an informed consent form and filled out the demographic information sheet. Interviews are conducted in the living room or the family room following requests from participants, and each one lasts about 40–60 min. Interview transcripts were analyzed using a data analysis process developed according to Collaizi.[11] The limitation in this research is that triangulation of sources, methods, and theories is not done.

Results

The detail of demographic information about the study participants is provided in Table 1. After conducting in-depth interviews with the participants, the researchers identified five themes.

The study results, namely the patient's perception of the disease experienced, perceived obstacles, factors that support adherence in treatment, hopes to achieve healing, and health promotion behavior in Table 2.

Theme 1: patients' perceptions about the disease experienced

Participants feel that the treatment they are taking has a severe impact and a dangerous disease. Feelings of deep anxiety and fear are felt, alienated, shunned, disrespected, and considered a humiliating and unclean condition.

Following are excerpts from participant interviews:

> ''.... *Because a doctor is explaining that the weight of the treatment...heavy... because it is confirmed as the doctor said it was cumbersome, not everyone can run it, serious times indeed... (P3)*

Theme 2: perceived obstacles

Participants revealed that drug side effects and length of treatment time were obstacles in MDR TB treatment. In addition, the negative attitude of health workers during the

Table 2 Superordinate themes and subthemes of the lived experiences of the MDR-TB patients.

Superordinate themes	Subthemes	*f*
Patients' perceptions about the disease experienced.	Understanding of the illness experience.	[5]
	Negative attitude when sick	[6]
	Stigma.	[4]
Perceived obstacles	Drug side effects	[6]
	Long treatment time	[5]
	The negative attitude of health workers.	[4]
Factors that support adherence in the treatment	Internal support	[5]
	Support in care	[6]
Hope to achieve healing	Desire and reason to recover	[5]
Health promotion behavior	A positive attitude by maintaining distance and use of masks	[5]

treatment and treatment period has made them lazy to take medication.

The following are excerpts from participant interviews:

''... I am weak...vomiting...if people talk sometimes, I don't hear enough...the sixth month of the foot aches in the bones in all parts of the body starting from the waist down and a few months later becoming dead taste like paralyzed'' (P3)

Themes 3: factors that support adherence in the treatment

Participants revealed that when they were in a state of decline and fear, all they did was recite dhikr, hear Alquran, and believe in the power of God. In addition, support in the care he received during the treatment period such as a source of support and support from health workers themselves in the form of motivation. Participants also revealed that what was just as important was family support.

Following are excerpts from participant interviews:

''Yes...that's...this is the fear that sometimes arises...then...Istighfar..'' (P2)

Themes 4: hope to achieve healing

Participants expressed hope that they could recover after undergoing treatment to return to good health and be close to their family and friends. They can carry out activities as before the illness.

Following are excerpts from participant interviews:

''..... I hope that I can still gather with friends.....that's hope...can still read the Alquran.....can still be with hugs and kisses..'' (P4)

Themes 5: health promotion behavior

Participants express positive attitudes in promoting themselves that arise from within themselves due to increased self-awareness about the disease they suffer.

Following are excerpts from participant interviews:

''... so my mother uses it... I also use this (pointing to the mask), so the communication is still a mask..'' (P3)

''... sit down...wear...(show mask)...if that person doesn't understand it... I keep the distance from him...'' (P4)

In this study, the attitudes identified during the MDR TB treatment period were anxiety because of fear of the disease they experienced leading to death, hopelessness, non-compliance in treatment, regret, and surrender to the condition of the illness they experienced. Feelings of pain, sadness, and despair because the illness suffered can cause death.[12] They feel other people's changes in the way they view and interact. Things that are felt like a disease experienced are shame, feeling ''discriminated,'' and disrespected. In this study, participants felt stigmatized health workers who often saw them as ''insecure'' and avoided interacting with participants. Stigmatization can be in the form of unfavorable treatment, conflicts that occur due to speaking, or painful attitudes of people; this conflict is overcome by the client patiently and surrendering to the powerful.[13]

Drug effect is an essential obstacle felt by MDR Sufferers. The most dominant effects of the drugs are nausea and vomiting. Nausea and vomiting are symptoms that often occur during the treatment period.[7] Another obstacle that is felt from the effect of the drug is psychological problems. Mental health problems are one of the impacts experienced by TB sufferers, mental health disorders related to psychological, emotional, and spiritual well-being.[14] Long treatment time, heavy drugs, and routine of taking large amounts of medication every day cause fatigue and boredom. The treatment in patients with MDR TB requires 19–24 months.[15]

The negative treatment experienced by health workers during treatment is like an attitude in providing services that makes them lazy to seek treatment. Negative attitudes of health professionals and lack of social support contribute to patients who fail treatment.[16] Increased communication between health care providers and MDR-TB patients and increasing their knowledge and understanding of treatment programs will create a sense of individual self-empowerment and increase their confidence in treatment.

One of the factors that support the adherence of MDR TB patients during the treatment period identified in this study is internal supporting factors such as spiritual coping and positive coping. Spiritual coping or religious coping is a way for individuals to use their beliefs in managing stress and problems in life.[17] Another factor influencing adherence in

treatment is support in care consisting of sources of support (health care facilities), forms of support for health workers in motivating treatment, and family support. Many factors influence long-term medication adherence. Health policymakers and practices can support long-treated MDR-TB patients by appreciating that MDR-TB conditions affect the psychosocial life of sufferers. Develop strategies to reduce perceived effects by providing opportunities to share their anxieties, suffering, and biopsychosocial change.

In this study, there is a desire to recover after undergoing MDR TB treatment and hope that no family members will experience something like this. The experience of clients who have experienced relapses and feel the heaviness of undergoing treatment in the hope that they can be completely cured and not relapse.[13]

The study's findings reveal the relationship between adherence behavior in treatment in MDR TB patients with HPM Pender's theory. One of the strengths of HPM is a behavioral judgment regarding prior behavior. In this case, previous behaviors and acquired characteristics can influence beliefs, feelings, and perform health-promoting behaviors. The positive attitude of MDR TB sufferers in self-promoting behavior to prevent transmission to other family members and the surrounding environment. The emergence of this attitude is due to experiences related to the past associated with the disease they are experiencing and an increase in self-awareness about their illness. Identifying and reducing perceived barriers to health-promoting behavior will improve the quality of patient care and facilitate planning for educational services in changing behavior. Because behaviors with positive influences tend to be repeated and behaviors with negative consequences are usually less duplicated, the influence related in this study is a good predictor for the occurrence of healthy self-care behavior in patients.[10]

Conclusion

During the MDR TB treatment, the patients suffered severely from the side effect of the drugs, the length of treatment, and negative treatment from some health workers, so they were lazy to seek treatment. However, the support of family and social environment, adequate service facilities, positive self-confidence, and spiritual coping from sufferers can increase treatment adherence.

Self-promoting behavior to prevent transmission to other family members and the surrounding environment can be done by wearing a mask and maintaining distance. The emergence of this attitude is caused by experiencing an increased self-awareness to prevent disease transmission.

Funding

This research was carried out with independent funding by the researchers.

Conflict of interest

The authors declare no conflict of interest.

Acknowledgments

We would like to thanks the nurses who assisted us during the data collection of this study.

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