

# Treatment Adherence among Tuberculosis patients: A Concept Analysis

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#### Abstract

**BACKGROUND:** The principal difficulty of long-term tuberculosis (TB) treatment is patient nonadherence. During pandemic, nonadherence of TB treatment affects mortality since TB patients are more vulnerable to COVID-19.

AIM: The purpose of this concept analysis was to clarify and analyze the concept of treatment adherence

**METHODS:** Analysis concept was conducted using the Walker and Avant's method from relevant studies published by EBSCO, PubMed, ProQuest, Wiley Online Library, and Springer in 2003–2021.

**RESULTS:** Five attributes characterizing the concept of treatment adherence from thirteen articles were identified: individual behavior, relationship, mutual participation, shared decision-making, and agreement.

**CONCLUSION:** This concept analysis revealed that TB treatment adherence involves many aspects, including the patient, family, society, health professionals, and policy. These findings help to understand the contribution of major attributes, thereby promoting the body of knowledge on TB and contributing to its elimination during COVID-19 pandemic.

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# Introduction

COVID-19 pandemic affects many aspects of life, such as health delivery system, education, economic, and social worldwide. Solutions are provided to prevent the transmission of virus such as physical and social distancing which impact special patient population that cannot visit healthcare facilities to obtain their regular medication treatment management [1], such as tuberculosis (TB) patients.

Before pandemic situation, Indonesia ranked third for TB infections globally. This is caused by primary reasons such as the patient felt healthy (37.51%), the patient did not go to clinic or hospital to take control (28.42%), other reasons (24.95%), economic limitations preventing routine medication purchase (17.3%), long-term medication (16.54%), medication side effects (15.66%), forgetfulness (8.12%), and medication unavailability in healthcare centers or clinics (4.72%) [2]. Although many programs have been launched and expanded in an attempt to decrease TB incidence, the decrease of TB is still slow. According to the World Health Organization (WHO), only 67% of patients in 2018 were notified regarding their TB status (570,289 of 845,000 people). This means that 275,000 people could not be reached by the National TB Services [3]. This situation is worsen by pandemic, which makes Indonesia ranked second of having the most TB infections globally after India, despite of the largest population and impact of pandemic situation that causes economic distress [4]. Each country regulation has personal restriction due to Covid-19 pandemic that influence patient to become afraid to visit healthcare facility. This largest TB population presents a greater burden to society.

COVID-19 affects healthcare delivery system so that its structure needs to be reorganized and evaluated to improve the stability of previous advance made in healthcare. More practical guidance must be built and created by integrating experiences and maintaining professional participation in decision making process to improve the patient care [5]. TB can be cured using pharmacological intervention that must be taken by TB patients for at least 6 months. Besides pharmacological intervention, some patients with TB require pulmonary rehabilitation such as physical training, breathing exercise, education, nutritional support, and psychological interventions [6]. Health professionals and family provide these interventions. However, outcomes can be negatively affected if the patients do not adhere to treatment due to personal and social restriction when visiting healthcare facility. Health professional, such as nurse should be aware of the risk of TB patients to get infected with COVID-19 in the health facility since both diseases can cause death.

Treatment adherence is a complex behavior influenced by many factors. Hence, in order that the treatment outcomes of TB patients are improved, full understanding regarding the factors affecting TB patients adherence until they complete their treatment are required [7], especially during COVID-19 pandemic. TB as a chronic medical condition has a great impact not only on the patient but also on the family's quality of life.

# Methods

This article applied an analysis method proposed by [8] consisting of eight steps: (1) the selection of concept, (2) the determination of the analysis purpose, (3) the identification of the concept use, (4) the determination of the attributes, (5) the construction of a model case, (6) the construction additional cases, (7) the identification of antecedents and consequences of the concept, and (8) the definition of the empirical referents. The purpose of this study was to construct the identified concept of treatment adherence from EBSCO, PubMed, ProQuest, Wiley Online Library, and Springer published in 2003–2021.

## Uses of concepts

This step defines the concept of adherence as written by different people and professional bodies. The concept of adherence can be found in online dictionaries, such as the Oxford Learner's Dictionaries and the Cambridge Business English Dictionary. According to Dictionaries [9], adherence is the act of behaving according to a particular rule, following a particular set of beliefs, or a fixed way of doing something. Meanwhile [10], defines adherence as the act of doing something according to a particular rule, standard, agreement, and so forth.

The treatment adherence term in the medical field refers to medication adherence. Medication is medicine that is regularly taken by a patient [11]. Many studies have been conducted on treatment adherence and medication adherence use the terms interchangeably. Medication adherence is defined as taking pills correctly based on prescribed treatment plan or as the extent to which a patient adheres to the prescribed dose and interval of their medication regimen [12], [13] or based on ratio of the number of days covered by medications to the total number of days within a certain period [14], [15] Broadly, treatment is defined as the process or manner of treating someone or something [11]. As treatment adherence is not limited to medication, the WHO defines adherence as "the extent to which a person's behavior including taking medication, following a diet, or executing lifestyle changes corresponds with the agreed-on recommendations of a health care provider" [16].

In nursing, [17] defined treatment adherence as a process by which an appropriate treatment is decided upon after proper discussion between health professional and a patient. Adherence is also defined as a nonjudgmental, mutual desire to achieve a specific behavior; it describes a shared decision-making process to follow recommendations [18]. Another researcher defined adherence as the relationship between patients and health professionals with respect and mutual cooperation [19]. Adherence also assumes an equal relationship between two or more people and is a voluntary process. In health care, adherence is related to making lifestyle changes, taking prescribed medication, seeking help if symptoms change, and attending consultations [20].

## The attributes

The concept of interest can be defined by identifying its attributes. Attributes are characteristics or words that frequently appear and have the same meaning in the medical and nursing literature. Contextual definition of treatment adherence identified through literature review and determines five important attributes: individual behavior, relationships, shared decision-making, mutual participation, and agreement.

## Individual behavior

Behavior is defined as any activity in response to external or internal stimuli that can be seen [21]. Two terms with the same meaning were identified in the literature review: process and the act of doing something. The multifaceted nature of TB treatment and intervention need to be highlighted [22], especially if TB patients experience COVID-19 infection that causes worse treatment outcomes. When TB patients start longterm treatment, they should be proactive and behave in the manner recommended by health professionals. Directly observed Treatment Short Course have been used as strategy to increase patients' adherence since long time ago.

Before pandemic, individual desire behaviors may include health-seeking behaviors including aggressiveness of treatment evaluation after first diagnosis of TB, taking regular medication, consumption of nutrients, improvements to lifestyle choices linked to more serious diseases, such as cigarette smoking and prevention of TB transmission [23], [24], [25]. Due to COVID-19 pandemic, there was an advance change that healthcare services are shifting to patients and caregivers taking of their self-care [26]. Many countries have restricted or reduced the need of TB patient to visit health facility for follow-up medication, scheduled diagnostic and regular medication. The strategies were changed into more useful system for the patients, such as remote treatment using telemedicine, collaboration with private healthcare provider, and the provision of community medicine collection points [27]. In term of telemedicine, research on 405 respondents at North India and England reported that there were 96.1 % respondents that used video to directly observe TB therapy which has high rates of treatment completion [28].

## Relationship

The concept of relationship is most often used to emphasize the interactions between two or more people, such as the relationship between patient and health professional. In term of relationship between TB patients, family and health professional, health professionals must engage in less paternalistic relationships [29], therapeutic and respect one another. In this case, the patient's needs should be the first priority. Therefore, health professionals should provide information to their patient, especially about their medical condition, treatment regimen and progress, treatment options available, the duration of treatment, potential side effects of medicine, and outcomes [25], [30]. When patients communicate concerns about their problems, health professionals can achieve a greater understanding of them [31]. Before pandemic, this relationship occurred at healthcare facilities in the forms of direct interaction (face to face) between patient, family, and health professional.

Unfortunately, the reduction of interaction between TB patients and health professional occurred during COVID-19 pandemic. In 2020, the WHO had urged all countries to maintain the continuity of essential services for people affected with TB during pandemic by shifting from directly observed therapy to self-administered therapy [26]. It also shapes the use of digital health technologies to provide and support information that TB patients need [32]. Relationships, even though using digital technologies, must be created with an understanding of patients' values and preferences. Based on the qualitative study that was conducted at Zambia, Brazil, Sierra Lone (Africa). TB patients shared their concern when visiting health facility. They worried of being diagnosed with COVID-19 in the health facilities and because of social stigma related to infectious disease [33], [34]. Health professional provides solutions to improve relationship with TB patients such as messaging TB patient about the time of health seeking behavior and informing patients with infection control measures taken at healthcare facilities [33].

Shared decision-making is another attribute of adherence. It is the process of interaction between patients and health professionals in which collaborative decisions are made regarding diagnostics, therapy, and treatment planning. Decisions should be based on evidence that balances the risk and outcome of the treatment choice. After health professionals provide all information through the therapeutic relationship, the patient must decide what is best for them.

Various factors influence the quality of shared decision-making, including the basic moral principles of the health professional. The health professional must show respects for autonomy, beneficence, no maleficence, and justice [35], [36]. These factors help to develop trust and cooperation between patients and health professionals.

Decision-making is a process that involves a high-level cognitive process such as perception, attention, and memory [37]. In terms of a lack of perception, attention, and memory to process the information required, health professionals must create strategies to promote patient engagement. In the process of engagement, health professionals should establish effective interactions with patients, their families, and peers [38], [39].

During pandemic, patient, family, and health professional can encounter problem when making decision. Based on a study to 1061 participants about participation preferences during pandemic at German through online survey, it was found that most participants expressed a strong need of information and moderate participation preferences when making a decision [40]. Beside patient, health professional also can encounter ethical problem when treating sputum positive cases of TB. Study was carried out at Pakistan to 100 health professionals including doctor, nurses and assistant laboratory found that participants tend to encounter ethical issues. This ethical issue including the lack of maintaining patient confidentiality, having poor knowledge of ethics basic principles, reducing patient autonomy by treating prolonged periods without their willingness [41]. This health professional ethical issue should be prevented by increasing training and knowledge about TB control programs and ethical principles.

## Mutual participation

Since TB is a disease that is highly correlated with economic and poverty distress [4], patients and families tend to accept medication given by the doctor/health professional, and then patient does not engage further in the treatment process that causes drug resistance. This situation describes medical consultation, not mutual participation. Patients should be encouraged to participate in their health care, even though the patients are less likely to participate in their health care due to several factors such as poverty, low education level, and living in remote areas [42]. Mutual participation will create a conducive atmosphere for decision making.

However, the provision of strategy using digital technologies by encouraging mutual participation still have tough challenge, especially for patients and family who have economic distress and coming from remote area. Many countries have configured methods to support TB patients with mobile health, remote consultation, Video Directly Observed Therapy, and short messaging text to provide continuity of TB national programs. In India, there was a quasy-experimental study that was conducted to 220 newly diagnosis TB patients using mHealth intervention, finding an increased medication adherence from 85.5 to 96.4% in intervention group [43].

### Agreement

Agreement refers to two or more people agreeing to an action, fact, or decision that resulted from an interaction. A general agreement is different from a therapeutic agreement. In the health area, agreements between patients and health professionals are therapeutic.

Agreements made by health professionals and patients are not limited to medication but also include diagnostic, preventive, rehabilitative, and promotive aspects. In a therapeutic agreement, the validity of the agreement should be based on voluntary participation. The patient must consider their agreement voluntary and must be duly notified of information by the health professional in charge [44]. Health professional should provide informed consent after educating the patients about the risks, benefits of treatment alternatives, longterm therapies, and additional TB treatments. Informed consent is defined as an ethical and legal obligation and it should be documented [45].

In 2003, the WHO had developed a strategy to improve adherence using contracts. This contracts are defined as agreement that could be in writing or verbal forms from the TB patients to follow the treatment including returning for appointment and evaluation of the treatment course [16]. Regarding pandemic situation, each healthcare facility has autonomy to determine whether to use written or oral contract.

#### Model cases

Alex, 40 years old, is a food retailer diagnosed with pulmonary TB through a set of diagnostic tests at primary health care facility. He planned to undergo a long-term medication and treatment, but he was afraid of getting COVID-19 while visiting the primary health care. Nurse contacted him through telephone to go to primary health care with one person of his family and informed him about the infection control measures that would be taken at the primary health care. When they visited the primary health care, nurse provided the infection control measures to convince him that they follow the health protocols. Before giving the treatment, nurse educated Alex and his family about his medical condition and regimen, including medication (dose, duration of medication, side effects), evaluation of treatment (e.g., by checking sputum), nutritional support information, lifestyle changes (e.g., quitting smoking), and scheduled diagnostic, while nurse paying attention to Alex and his family responses.

Alex and his family concern about regular medication and scheduled diagnostic when pandemic situation occurred but nurse provided solution, where she gave her number so that they can contact her to follow the regular medication, scheduled diagnostic or if Alex have side effect of TB Medication.

After small discussion, Alex was asked to sign his informed consent form and he gave it back to the nurse. While undergoing the treatment, Alex behaved in the way he discussed with health professionals regarding changing his lifestyle and adhering to his medication. His family also supported him in adhering to treatment.

This model case contains five attributes of treatment adherence: Individual behavior, relationship, decision making, mutual participation, and agreement. When Alex and family decide to take long-term medication as recommended by nurse, nurse maintains their relationship by providing information about TB treatment, despite of the pandemic situation. TB treatment is not limited to taking medication regularly; there are also additional treatments that are discussed with the patient, including the risk of treatment at the ongoing pandemic. Health professionals should listen to patients' and family's concerns, respect and should not be judgmental of patients with TB. Through pandemic, health professional provide solution to guarantee the continuity of national TB program, by providing solution using digital technologies. When health professional use digital technologies as solution, they also must understand about patient's value and preferences. If patients were in the remote area and do not have device to follow the treatment, health professional must provide other solution according to TB patients need.

After health professionals provided information to patient and family, they discussed about treatment concerns. After that, the patient should decide about the treatment. This is documented through agreement or informed consent. The informed consent is signed by the patient and family to ensure their participation willingness during the decision-making process.

#### Additional cases

Jake, 43 years old, has been diagnosed with pulmonary TB at primary health care and has

begun his treatment. After taking his medication for 1 week, Jake was surprised to find that his urine was reddish and that he felt nausea. Jake contacted nurse through telephone and he said that he did not want to continue the medication, because he felt not healthy after taking the TB medication. Nurse was asked patient to continue the medication, if he did not continue it, he could die. Nurse then provided information about the side effect of medication in the telephone and solution to reduce nausea. Besides that, nurse also asked him to continue his medication, if the side effect continues to happen, he was asked to go to the primary health care and follow up his condition.

This borderline case contains two out of five components of treatment adherence: Relationship and individual behavior. However, the case lacks decision making, agreement, and mutual participation. Longterm treatment will impact an individual's life through medication side effects, feelings of boredom, the influence of treatment on activity or work, and so forth. This must be communicated with the patient before they decide what to do to maintain their health. Nurse should provide as much information as possible, including alternative options or treatments, as well as the advantages and disadvantages of each treatment. If patient receive information early and appropriately, they can be prepared for the side effects of their medication and not seeks other solutions, such as ceasing the medication. In COVID-19 pandemic, in term of creating relationship with health professional, TB patient can contact or share their problem to health professional in charge, so health professional can provide solution to prevent the transmission of COVID-19 to TB patients.

#### Contrary case

According to Walker and Avant [8], contrary case analysis is an act or scenario that is unrelated to the concept.

Clara has been undergoing treatment for TB for 1 month. She has not taken her medication regularly because she has felt healthy and her cough has reduced. She also has not taken her medication regularly because she has to work and, therefore, did not have time to get her medication. After 1 month, a nurse reminded her to check her sputum to evaluate her medical condition and medication. Clara did not follow this recommendation. She also reverted to previous harmful lifestyle choices, such as smoking and consuming alcohol. Clara did not adhere to her treatment despite the fact that she agreed to it and gave her informed consent before beginning the treatment.

This case shows none of the defining attributes. This contrasts with the model case, which included all the attributes.

## Antecedents and consequences

#### Antecedents

Events that occurred before an existing concept are antecedents. TB requires a full understanding of the factors influence adherence of the treatment, thus assist TB patient to complete their treatment [7].

The reviewed literature revealed two major antecedents: Internal and external factors. Internal factors are derived from inside patients. Many studies have reported on factors that influence adherence to TB treatment, including age, employment, and lifestyle choices, such as consuming alcohol [46], [47]. Other intrinsic factors that influence treatment adherence are knowledge about TB [47], [48], [49], including drug side effects and having a positive self-image and self-awareness [50]. In contrast to adherence, a factor that influences nonadherence to TB treatment is the side effects of the medication. Patients tend to develop anxiety when they do not understand the side effects. During pandemic, many patients experienced fear, worry, and insecure when the patient go to health facility or medical appointment [51].

External factors are derived from the outside of the patient or individual. External factors that influence adherence to TB treatment consist of three aspects: family and social environment, health professionals, and policy. Support comes from family members, including family members that supervise TB medication frequently and provide spiritual encouragement [48]. Encouragement provided by family members can increase patient confidence in adhering to treatment. In addition to family, support from the patient's social environment is also required [52].

Another external factor has to do with health professionals who have good relationships and communication with TB patients [48], and provide psychological counseling [12], [49]. The relationship between health professionals and patients can be improved by health professionals by providing strategies, such as home visits and telephone supervision [53]. Health professional training also needs to maintain the ongoing work of TB program at the health facility [54].

Finally, the last factor is policy. Many patients in this present study specifically in North-Eastern China, Dalian did not aware for national treatment policies. This country has established policies for free TB treatment such as free medication. However, the expensive cost of diagnostic and adjuvant drugs are not included [48].

#### Consequences

Consequences are defined as the result of a concept [8]. Regarding COVID-19 pandemic, the consequence of TB treatment adherence prevents TB patients to be infected with COVID-19. Other consequences include preventing transmission of the disease for other family members, improving quality of life, and avoiding drug resistance.

The consequences of nonadherence to TB treatment include prolonged infectiousness, drug resistance, relapse, and death [55].

#### **Empirical references**

According to Walker and Avant, the last step for concept analysis is defining the empirical references [8]. Empirical instruments can be used to measure and evaluate TB treatment adherence.

In this case, empirical tools include knowledge and beliefs about TB treatment; perceived facilitators and barriers to adhere TB treatment. TB medication adherence can be measured using TB Medication Adherence Scale which involves nine factors: communication with healthcare providers, personal traits, confidence in curing TB, social support, mood disorder, living habits, active coping behavior, forgetfulness, and access to health care facility [56].

For patients with drug resistance, the Adaptation Status Assessment of Drug Resistant TB patient is a validated instrument. It involves four factors: physiologic function, self-concept, role function, and interdependence. This instrument is reliable and valid for measuring the adaptation of patients with drug-resistant TB [57].

Since 2015, the WHO has been urging the implementation of digital adherence monitoring technologies as strategy to End TB [58]. In addition, due to the presence of COVID-19 pandemic, many research projects have focused on creating such technologies, such as medication event reminder monitor. This technology is a real-time medication monitoring device that provides short messages to improve TB treatment adherence

The service content from this technology consists of five aspects, there is supervision method for daily dosing, follow-up visit reminder, monthly follow-up patient visit to doctor, judgment and handling of missing doses, as well as doctor to patient visit (Figure 1) [59], [60].



Figure 1: Illustration of the medication event reminder monitor for tuberculosis patients [59].

### Discussion

This study analyzed the concept of treatment adherence among TB patients in the context of pandemic situation even though few of the contextual definitions were identified from reviewed literature before pandemic situation. Five attributes that identified still relevant with the context of pandemic situation.

For example, individual behavior that includes knowledge, affective, and psychomotor still become factors that influence number of TB cases and transmission. When TB patients are diagnosed and planned to follow the treatment, health professionals, such as nurse must create good relationship with the patients, and also with the family in accordance with pandemic situation by following the health protocols. Nurse's social support influences the TB treatment adherence and it became critical issue of the drug resistance development. Emotional support, instrumental, and support seeking will decrease TB patient's nonadherence [61].

When patient is diagnosed with TB and before patient undergo the long-term treatment, health professional should provide information about the treatment, including benefit and risk of treatment. After that, patient and family should decide the best for patient. Inform consent is needed as a result of patient's decision making and agreement. This agreement will provide patient participation to adhere to the treatment. Hence, nurses as care provider must have concept regarding TB control program [41] in each health care facilities, so that health professionals, including nurses will not encounter ethical dilemma when taking care of TB patients.

Concept analysis of treatment adherence is one of important stages in theory development. These attributes could be used as a guide for further development of nursing practice and nursing research.

## Conclusion

Based on the literature reviewed, this article has clarified and interpreted treatment adherence as it relates to cases of TB during COVID-19 pandemic. Adherence to TB treatment involves multiple main aspects to reduce the transmission of TB as well as to decrease mortality and the social burden. Research in the fields of nursing, psychology, and medicine have addressed the importance of adherence to TB treatment since TB patients is also vulnerable to get infected with COVID-19. This article has also provided a conceptual meaning of adherence that provides foundational work for model development in treatment adherence.

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