

# FAMILY LIVED EXPERIENCE IN TREATING PATIENT WITH SPONDYLITIS TUBERCULOSIS IN INDONESIA

Yosi Handayani<sup>1</sup>, Neti Juniarti<sup>2\*</sup>, Ahmad Yamin<sup>3</sup>

Faculty of Nursing, Padjadjaran University

<sup>1</sup> Student of Faculty of Nursing Unpad

<sup>2</sup> Lecturers of Basic Nursing Faculty of Nursing Unpad

<sup>3</sup> Lecturer of Community Nursing Faculty of Nursing Unpad

\*Corresponding author: [neti.juniarti@unpad.ac.id](mailto:neti.juniarti@unpad.ac.id)

Received: 12 May 2020 Revised and Accepted: 09 July 2020

**Abstract:** Many studies have shown that patients with TB spondylitis are late treated. The cause of the delay has not been known, but the reactions to treatment, and lack of information about the disease. The family has an important role in preventing disease expansion and TB spondylitis complications for both the patient and the environment. The purpose of this study was to find out how to experience TB spondylitis in Bandung West Java. TB spondylitis. The research method used was descriptive phenomenology that focuses on the search for meaning and has a limited number of participants. Participants in this study were 10 patients with the primary care of TB spondylitis. All participants are women, six are mothers, two wives and two sisters. Data collection techniques in this study with documentation studies, in-depth interviews and observation. The analysis used in this study was an in-depth description of family experiences treating patients with TB spondylitis. In this study found four themes include: (1) TB spondylitis disease as a "confusing" disease. Consisting of two subthemes namely: (a) mechanical injury, "bullied" person, and instant food "accused" as the cause of TB spondylitis (b) An exhausting back and forth phase, Consist of: (a) changing Internet service provider (b) Alternative Treatment (c) Medical Treatment (3) Family Efforts in caring for Patients with tuberculosis spondylitis Consist of: (a) Family care when patient "can not do anything (b) Patiently facing the test of life (4) Family Expectations on Health Services, consisting of: (a) Ease of reaching the health services of patients with TB spondylitis (b) Good communication from health providers.

**Keywords :** Family life experiences, caregiver burden, TB spondylitis, phenomenology

## I. Introduction

The incidence of extrapulmonary tuberculosis that had the worst complication was TB spondylitis and incidence rate of TB spondylitis in Indonesia increased significantly each year (Paramarta, et al . , 2008). Research in Iran by Alavi & Sharifi (2010) also explained that most TB spondylitis patients seek treatment after complications so that handling becomes more difficult. The cause of the delay is not widely known, but there are allegations of delayed referral, rejection of treatment, and lack of information about the disease (Alavi and Sharifi, 2010). The family has an important role in preventing disease expansion and TB spondylitis complications for both the patient and the environment. The family is also a major determinant of the search for health care for members of his family (Friedman, 2010). Moreover, patients with TB spondylitis usually experience paralysis so require assistance from caring family.

According to Pratt (1976) in Friedman (2010) explained that family reasons have difficulty in providing health care for their family members lies in (a) family structure and (b) health care system. Knowledge of how to care for the patient, how the disease arises, how the family understands TB spondylitis disease and how families

seeking help need to be explored more deeply so that it can become a reference in improving the function of family health care.

Experience on how to treat the family with TB spondylitis provides an overview of the family's need for proper treatment. The results of the study are expected to be a source of nurse knowledge to identify the expectations and needs of the family on health services at the beginning of the disease, an effort that can be done during treating patients with TB spondylitis, prevent the expansion of TB infection in the family, prevent the occurrence of complications, disability, and death due to TB disease. Based on the above two cases illustrate the patient service TB spondylitis experienced a deterioration in health even experienced the same disease. This should be studied more deeply about the causes of worsening of disease and transmission of the same disease in the family.

The meaning of a problem can be extracted by examining the history of the past related to the current situation so as to provide solutions in the future. An understanding of family experiences treating patients with TB spondylitis will be obtained directly from the source experiencing it by conducting a qualitative study through the approach of phenomenology. Phenomenological research is the study of life experiences, a deeper understanding of the nature or meaning of the experience of everyday life, discovering the meaning or nature of human beings and then rewriting the "memories" or core that we may never have thought or felt before (Van Manen 1990). According to Denzil and Lincoln (2008) The description of a person's experience of past history and future projections (time) and whatever happens in space can be investigated by a descriptive phenomenology approach. To understand how families interpret their role as caregiver; what is the meaning of care for family members, how families care for family members with TB spondylitis will affect what the family does when treating members affected by TB spondylitis. Thus we will get a true picture of the causes of complications, severity of the disease and transmission that is difficult to control.

Increased number of patients TB spondylitis is suspected due to late diagnosis, environmental factors, lack of prevention of TB transmission of TB, inadequate OAT treatment, comorbidities that lead to decreased immunity. So the research will focus on descriptive phenomenology approaches on the grounds that this approach emphasizes the discovery of the nature and meaning of the daily family experience of caring for patients with TB spondylitis. Past health history in the family, how the family strives for health and cares for it right now. How family expectations for the healing of sick family members and health expectations for each other family members can be explored by phenomenological research approaches. Besides understanding about the existence of space and time are related to environmental factors, family economy, attitudes and behavior in the family can be known through research with phenomenology approach. Therefore it is necessary to research about how the experience of families who care for patients with TB spondylitis, to formulate various policies related to TB management in various order of primary, secondary and tertiary services with nursing process approach.

## **II. Methods**

The approach used in this research is descriptive phenomenology. Focusing on how the right dideskripsi life experience, how a meaning constructed (Streubert and Carpenter, 2007). The specificity of phenomenological research by Denzil and Lincoln (2008) is the focus of research in the search for meaning and has a limited number of participants. In addition, the method of collecting data by way of in-depth interviews so that the results obtained is a deep reflective description of the experience associated with how it feels to treat patients with TB spondylitis.

Phenomenology is one of the qualitative research design that has a sense of their exploration efforts and understanding the meaning of what is happening in the various individuals or groups, which are derived from social or humanitarian problems (Creswell, 2010). According to Giorgi (2011) that in finding a meaning, the researcher must have an open attitude to let the meaning appear unexpectedly. In contrast to quantitative research that feels "knowing what is unknown", raises the question: "how do we describe the *valid* meaning of quantitative data?". While in qualitative research, researchers feel "do not know what is known". The qualitative research design developed is likely to be open to any necessary changes and flexible to existing conditions in the field (Zuriah, 2006).

Phenomenological research aims to gain a deep understanding of the nature or nature of everyday experience family caring for patients with TB spondylitis. The core of this research is the idea of the living world, understanding that the reality of experience in caring for a family with TB spondylitis can be understood through a k e wildlife caregiver TB spondylitis day - day. This study gives attention to awareness about the

process of treating patients with TB spondylitis, awareness of its role as caregiver of patients with TB spondylitis. In this study reflect back the meaning of the words that appear among the phrases "confused", "sad", "tired" and "patient" that describes the main "memories" felt by families who care for patients with TB spondylitis . Excavations about the meaning of feelings expressed by the family will reflect a picture of the meaning of caring and what happens when caring for families with TB spondylitis. It was then decided that the memories would be rewritten so as to illustrate the problems, challenges and expectations of the source. This will be useful for service providers, especially nurses to formulate primary, secondary and tertiary prevention.

Researchers previously read the results of previous research that many of the delays that occur patients with TB spondylitis. However, the cause of the delay has not been widely known. There are some conjectures but have not been proven by research. This needs to search for information by looking at the phenomenon of possible problems. The phenomenon can be implemented by interpreting the existence of one's experience seen from the perspective of space and time. This study illustrates the meaning of family experience by grouping data and formulating the meaning contained from a common and unique phrase. This can be reflected as a situation that describes the family experience with TB spondylitis. The stages involved are in the appendix.

Family life with family members with TB spondylitis certainly different from other families. Factors suspected to cause an increase in TB cases with complications. These factors are closely related to the meaning of space and time that characterize phenomenological research. Past history until the occurrence of the disease, family efforts to heal family members and prevention of transmission, family knowledge about disease, knowledge and family attitudes in caring for patients TB spondylitis is a component that needs to be known.

**III. Results and Discussion**

Characteristics of participants are presented in Table 1.

**Table 1 Characteristics of Participants**

Name Participant s	Participa nt Age (Year)	Level of educatio n Participa nts	employe nt history Participa nts	Relationshi ps with patients	Phase and Category OAT	Patient General Conditions during the interview	Operating Procedure Patient	History of Patients' TB Disease
Kikim	24	SMA	Work	Wife	Intensive, category 2	Crisis, deformity without injury	Operation Preparation n	Not excavated
Febi	42	SD	Does not work	mother	Intensive, category 2	Crisis , abscess sores	Operation Preparation n	Not excavated
Lina	45	SD	Does not work	mother	Intensive, Category 1	Crisis , deformity without injury	Operation Preparation n	Contact History
Rose	39	SD	SMA	mother	Intensive, Category 2	Stable , unformed deformity	Operation Preparation n	Contact History
Kokom	45	SMA	Does not work	Cousin	Advanced, Category 2	Stable postoperati ve wound	Post Operation	Never take OAT
Elis	58	No school	Does not work	mother	Intensive, Category 2	Stable , postoperati ve wound	Post Operation	Contact History
Reni	27	SMA	Work	Wife	Intensive,	Crisis ,	Operation	

					Category 2	deformity without injury	Preparation	Disconnect OAT
Sinta	23	SMA	Does not work	Sister	Intensive, Category 2	Crisis , second post operative injury wound	Post Operation	Never take OAT
Yani	55	SMP	Does not work	mother	Intensive, Category 1	Crisis , postoperative wounds	Post Operation	Not excavated
Neneng	49	Bachelor	Work	mother	Advanced, Category 1	Stable , unformed deformity	No Operation	Not excavated

In this study found four themes include: (1) TB spondylitis disease as a "confusing" disease. It consists of two subthemes namely (a) mechanical injury, "dijailin" person, and instant food "accused" as the cause of TB spondylitis (b) Family anxiety about "How" health status of patients with TB spondylitis (2) (b) Alternative Medicine (c) Medical Treatment (3) Family efforts in caring for patients with TB spondylitis Consisting of (a) Family care when the patient "can not do anything" (b) ) Patient facing trials (4) Family Expectations on Health Services (a) Ease of reaching the health services of patients with TB spondylitis (b) Good communication from health providers.

In this study the family describes its role as a care giver since the onset of symptoms, through the crisis phase until the current treatment is a long, confusing and exhausting journey. All participants "accuse" the cause of TB spondylitis is the result of mechanical injuries falling, sprains and accidents. It is also because of the energy retained in the patient's body as a result of the supernatural powers of others who dislike the success of their family. Families give the term "dijailin" people. In addition, families associate TB spondylitis with past habits of eating instant food in packaging. Families are unaware that environmental factors such as the history of contact with TB sufferers and being in the endemic areas of TB are the major factors of TB spondylitis (Alavi & Sharifi, 2010; Weng, *et al .*, 2013; Kim, *et al .*, 2016) . From the results of the study found the data that most patients have a history of contact with patients with pulmonary TB. In addition, from the results of observations during the interview, the patient's home environment is in the sunlight and are in a densely populated environment. This indicates that the actual cause of TB spondylitis is an environmental factor that is the transmission of TB disease from the surrounding environment.

Health and illness behaviours are closely related to differences in social class and ethnic background. Interpretation health and ill are defined as the natural state of living conditions so that the growing myths, values regarding their health. Socioeconomic positions greatly affect the interpretation of individual symptoms, whether the symptoms are considered as symptoms of sickness or not, thus affecting the search for medical treatment. In low socio-economic families reported to have less need for medical services (Koo, 1957 in Friedman, 2010). In this study it was found that the whole family revealed that the major obstacle felt when treating patients with TB spondylitis was cost. In addition to cost, distance and changes in the role of breadwinner in the family. However, they are closely related to costs, namely the distance associated costs incurred for other costs and operations while the role change is also related to the livelihood (cost) in the family.

The ethnic background of the family is another major factor affecting the concepts and beliefs of health and illness. Western societies typically base their explanation of the healthy illness of natural phenomena that is scientific findings; infection, mechanical injury, tumor growth, or stress effect. While non-westernized people consider the cause of the disease due to a supernatural phenomenon so that disease therapy generally corresponds to a belief about the cause of the problem (Kleinmann, 1980 in Friedman, 2010). Beliefs about the cause include the growing myths about the causes of disease because of supernatural powers affect the readiness of patients and families in search of medical health services. This is an individual's readiness and willingness factor in seeking health services and improving his lifestyle, as well as influencing preventive measures for

himself and other family members (Friedman, 2010). Families associate commonly bone diseases or bone fractures are the result of mechanical injury. Although, the history is only linked to no immediate incident that happened to the patient at the time. So the family sought the help of shamans or serialists to deal with the symptoms of the disease. It is also a myth that develops due to supernatural powers so that treatment is also related to treatment with supernatural energy evidenced from family allegations with the term "dijailin" people.

The stigma attached to patients with TB disease is a barrier to getting families the right treatment. According to Juniarti and Evan (2010) that *stigma* is still attached to people with TB disease in the community as a "dirty" disease, "death penalty" disease, and "poor" or lower-class disease. This causes patients and families to feel ashamed to hide their illness from others (Juniarti and Evan, 2010). The history of TB disease in the past and the history of contact with TB sufferers have been difficult to excavate because the family did not tell the truth about the illness from the beginning of treatment to the health care workers. Need specific strategies to explore information related to previous TB disease history. Friedman (2010) states that the family has a very important role in the sustainability of a family's health. Evident from the results of research on family families who care patients TB spondylitis that the family conducting treatment search and initiating treatment is highly dependent on the negotiations undertaken within the family. The family also acts as a referrer who will take his family members to the primary care source, and choose the type of service. The accuracy of selection of health facilities, adequate treatment and care is largely determined by the decision of the family to contact health services (Friedman, 2010). In this case the family has a very big role in determining the healing of the patient's illness from the beginning because the treatment decision depends on the caring family. Patients with TB spondylitis are in a state of paralysis and severe pain or with the term "nothing can".

In studies of TB spondylitis it was found that most families were delayed so treatment became difficult and long ( Alavi & Sharifi, 2010; Weng, *et al.* , 2013; Kim, *et al.* , 2016). In a study conducted by Alavi and Sharifi (2010) that patients with TB spondylitis experience delays in getting the disease handled. This is allegedly due to four factors including (1) delay in obtaining referrals from health workers for TB examination and treatment, (2) Rejection of the stigma-related condition that develops in the community about TB disease (3) At least information or opinion about TB spondylitis not a common disease (4) Inadequate previous specific TB treatment.

Allegations of delays expressed by Alavi and Sharifi (2010) are evidenced from the results of research on families caring for patients with TB spondylitis in West Java Bandung that patients are handled after being in crisis or late handled. This is due to family confusion about the cause of the disease and allegedly related to the myth that causes disease so that the search for health assistance to be late. In addition, information related to TB spondylitis disease is still very rarely socialized by health personnel. This is evidenced by the statement of all participants that since arriving in primary care the family did not get an explanation about the alleged TB spondylitis disease so that patients experience complications.

Complications that occur in patients with TB spondylitis cause a total dependence of patients on the family. This is because the long and tiring treatment procedures include severe pain, surgical wound and abscess sores. The family faces the challenge of pus and blood on the wound, a severe pain that causes the family to be awake. In addition, families face the challenges of severe pain that require treatment such as distraction of pain and other assistance related to the fulfillment of patient needs. Paralysis causes the family to provide total relief to fulfill the patient's basic needs. Nutrition fulfillment with challenge of side effects of OAT . Personal hygiene and the challenge of infected wounds.

Research on families caring for patients with pulmonary tuberculosis in South Africa suggests that the difficulties facing families caring for patients with pulmonary TB include adequate nutrition, OAT side effects, and difficult environmental modification (Sukumani, *et al.*, 2008). If all is done only by one care giver then it will be difficult to materialize. A caregiver feels a heavy burden when planting vegetables, raising and other crops as well as ensuring the patient is taking OAT properly. Modification of the environment will also be difficult to implement because it requires cost and many facilities. This makes the family frustrated and tend to perform maintenance "sober" so that patients experience less than optimal conditions. All participants said that the family has even been facing a crisis in the family that is difficult both physically, mentally and financially. Role changes - caring for "non-existent" patients, drug side effects, and "back and forth" treatments lead families to sacrifice the time, effort and cost to care for sick families. The family also expressed confusion and hoped to find a way out for the problems facing his family.

In addition to facing difficulties in treating, cost constraints, time and effort. Families who treat patients with TB spondylitis face the threat of contracting the disease because TB is easily transmitted through droplets . Families who treat potential infectious TB especially with weak physical and mental. This is revealed by

Friedman (2010) that family social irregularities with TB are bad for the health of other family members. Although not a hereditary disease such as Huntington disease. However, TB spondylitis mostly has active pulmonary TB disease, so families also face a "scourge" that "haunts" the family and can strike at any time when physical weakness.

In addition, some families also face abscess sores that leave the smell and feelings of disgust. The caring family should think about how to control the exudate out so as not to leave the rest of the dressing. How to modify dressing to improve comfort and prevent leakage. The care giver should find a way to do a wound dressing not to aggravate the wound causing bleeding and widespread injury (Probst, *et al.*, 2014). The results showed that families caring for patients with TB spondylitis were still confused about the abscess wound so that the handling was still "roughing". Among them bandage with kassa and let open wounds. Until the interview is done some families do not know the most appropriate way to deal with the wound exudate.

The length of the family trip in search of treatment from early diagnosis to treatment and surgical procedures, makes the family feel tired, confused and the threat of contracting TB disease. This is a challenge facing families who care for patients with TB spondylitis. The results showed that all participants stated that patience is a solution that can answer the challenges that are being faced. The family defines the difficulties facing the family as "the trial of life of God" and as the "deposit of God" to be performed with sincerity and gratitude. Research conducted by Maxted, *et al.*, (2014) on families caring for HD patients "We fight against the world" as an expression of solutions to family problems and efforts.

The family defines his role as caregiver of patients with TB spondylitis is a "Confusing and Exhausting Long Journey". Some participants regretted his actions did not prevent the habits of the past. Family anxiety about the health status of patients with TB spondylitis is described with the phrase "Fear gimana-gimana". The perceived anxiety caused by unexpected causes, fear of disease will get worse, fear of surgery procedures and fear of contracting the same disease.

Families who treat patients with TB spondylitis are "a confusing state". Families have made various attempts to deal with the symptoms that appear but, instead of improving, the longer they get worse. The family revealed that the search for relief for families affected by TB spondylitis was a "back and forth" effort that alternated both medical and alternative services, but never recovered. At least there are at least four places where families seek treatment for their families, including: alternative medicine (dukun, ustadz, smart people, herbal, acupuncture), Puskesmas or FKTP, secondary hospitals, and Tertiary Hospital. Families make efforts by alternating places of service both medical and alternative. This is expressed as the "back and forth" phase of the family for a period of one to four years to date. The journey starts from mild symptoms at home and self-care measures are performed, sorted, warmed oil, warm compresses and distractions but the family feels that the business is not working.

The family took the patients to treat various places, changed the alternative medicine for a long time. The family declared no change even worse, so the family went back to seek medical services. Thus the family goes back and forth and alternates treatment from alternative to other alternatives to kemedis then to alternate back until finally to the tertiary care where STB treatment currently is. The long journey has not ended because families are facing diagnostic procedures in some places. Starting from orthopedic poly, then poli deep disease, poly DOTS and back again to orthopedic and ending back in poly DOTS. So long the journey experienced by families and insufficient explanation makes the family experience anxiety expressed with the word "confused", "fear", "panic" and "sad". The efforts of the family in dealing with the problem are described by the expression "struggle", "sacrifice", "patience", "test", and "trials". The family hopes to get out of a long, bewildering and exhausting journey. The phrase conveyed by the family is "hopefully there is a way out".

The family's expectation of health care is the affordability of therapeutic and easy health services. This includes distance and ease of information. This hope can actually be realized if disease management can be done correctly since the onset of symptoms. Patients with TB spondylitis disease will recover quickly and treatment is shorter if handled since the onset of symptoms before bone damage (Alavi & Sharifi, 2010; Weng, *et al.*, 2013; Kim, *et al.*, 2016). Of the ten participants there was one participant who experienced a shorter recovery because of the early treatment of symptoms that is one year from the beginning of the emergence of symptoms.

The confusion expressed by all participants and the expression of wanting to get easy service is a picture of the lack of information about TB spondylitis since the onset of symptoms. The severity of the disease occurs because of the old TB germ invasion, causing bone pulp. If proper handling and information are obtained from the onset of symptoms, the patient will not fall into "nothing" or the crisis phase. In penelitan in patients with osteoarthritis (OA) by Miller, *et al.*, (2016) found that the professional relationship is a partnership with health professionals who help develop and revise the personal self-management plan. helping to change arthritis

treatment, shifting the health system from an acute episodic model or there has been a severity of becoming a yakit management since the onset of the illness.

The patient's need for information includes (1) what matters most to OA patients, (2) references to reliable information - appropriate sources of information, (3) information on the development of OA and appropriate management, (4) evidence of effectiveness drugs and expected maintenance management strategies; (5) access to OA experts; (6) choice and support; (7) partnerships with health care providers; and (8) re-access when more help is needed. The description of patients' needs with OA on health care is "supporting us in managing a meaningful life with OA" (Miller, *et al.*, 2016). Similarly, in patients with TB spondylitis, information on (1) The likelihood of disease occurring in families who have contact with TB patients, (2) previous history of TB disease, (3) Being in TB endemic areas (TB enclave areas) the symptoms of back pain that did not heal after being given treatment should be immediately decomposed with TB spondylitis and immediately get a proper medical examination.

A definite examination of TB spondylitis is through a biopsy on spinal lesions however, this is difficult in primary care because it requires specialists. A simple test that can be performed and proven to be effective is the examination of the erythrocyte sedimentation rate or the term often known as the Blood Endaple Rate (LED) and spinal x-ray or spine x-rays. If there is a change in bone structure, or there is a specific picture of bone infection should be immediately investigated regarding previous TB disease history or contact history. After it is validated by an LED examination, If an increase of normal value is found, then TB spondylitis treatment should be done immediately to prevent the severity. This was disclosed by several studies that p rosedur examination and discovery of cases through various stages including blood tests, in patients TB spondylitis is usually found to increase the rate of sedimentation of erythrosi (Alavi and Sharifi, 2010; Weng, *et al.*, 2013).

In a study conducted by Alavi and Sharifi (2010), laboratory results of TB spondylitis patients were found: 92.8% of ST patients experienced an increase in erythrocyte sedimentation rate (ESR) and positive *C-Reactive Protein* (CRP) of 86.9%. Patients with kecurig aan disease TB spondylitis performed a biopsy and bacterial culture found k Uman TB lesions and abscesses. In addition, there is a patient of TB spondylitis, there is a description of bone changes in radiographic scans and MRI. It's also worth it suspected of finding patients with high ESR and or positive CRP, age of adult or elderly, male gender, undergoing chronic peritoneal dialysis.

In addition to the range of information participants also expect health workers to understand that families with TB spondylitis have a long journey to arrive at current treatment. Families experience fatigue and anxiety about the development of the patient's illness. Therapeutic communication is required in conveying information to the family. In a study conducted by Feng, *et al.*, (2009) in Taiwan, in families caring for people living with HIV / AIDS, it was found that families felt stressed about the disclosure of their HIV / AIDS family status and the stigma that developed in the community.

Families are also concerned about the patient's social relationships with his community. The important things to know about families that treat patients with HIV / AIDS include information on the development of family illness, training and treatment procedures, and the side effects of treatment performed on patients with HIV / AIDS. The stress felt by the caring family is closely related to the needs of the family and is very influential to the quality of family life that cares for patients with HIV / AIDS (Feng, *et al.*, 200). Similarly, families with TB spondylitis, the family experienced stress due to uncertainty of health status both themselves and patients. In addition, the stigma that developed in the community caused the family difficulty in communicating their needs. This will have an impact on the quality of life of both the patient and the caring family.

The results of research on families treating patients with HIV / AIDS in Taiwan include: high levels of stress, high care needs in patients with HIV / AIDS, and low quality of life. This is a consideration for healthcare workers to provide assistance to reduce the burden felt by families, especially in families that do not have other families (only alone) and in parents who care for their children suffering from HIV / AIDS (Feng, *et al.*, 2009). A study conducted on a family caring for a patient with TB spondylitis found that the primary care family was a mother of six participants, other than a wife (two) and a sister (two).

The main family cared for is mostly a mother and wife who have a great love for her child or her husband. They have a stressful vulnerability in the face of family diseases they love. According to Campbell, 2000 in Friedman, 2010, the person caring for someone he loves sometimes experiences greater stress than the sick patient. Women have a higher potential for stress than men. This is a consideration for health workers, policy-related stakeholders who have to do with families with TB disease.

Health workers should be aware that the disease TB spondylitis field instead of "no" yet, it could be something that is "hidden". Sensitivity is required by healthcare workers both physicians and community nurses in the field

so that TB spondylitis can be found and treated early. In addition, families who provide patient care with TB spondylitis need help with the burden of perceived burden and possible TB disease.

#### **IV. Simpulan Conclusion**

Based on research and literature review concluded that patients with TB spondylitis experienced delays in treatment. This is due to false perceptions of the cause of the disease so that it continues on the wrong handling in the early stages of the disease. The family did an old alternative treatment that caused delay in handling. The length of the journey in finding the right treatment makes the family should take "back and forth" treatment between alternative medicine to one another and medical treatment from primary, secondary, to tertiary care.

In addition, long diagnosis of the procedure to make the family experiencing confusion and fatigue. Anxiety is also experienced by patients and families due to prolonged and painful medical procedures. Delay in diagnosis and treatment leads to complications that add to the extent of problems experienced by patients and families such as the cost, time, distance and role changes that occur within the family. Yet according to the results of research says that the right treatment at the beginning of symptoms appear to minimize complications and shorten the healing process, and get better results.

From the results of research related problems faced by families who treat patients with TB spondylitis can describe the problems that may not be answered in this study, following the theoretical suggestions for further research:

1. More in-depth research on the cooperation between Tertiary Hospital, Secondary Hospital and FKTP related to the accumulation of TB spondylitis patients in Tertiary Hospital.
2. Research on the effectiveness of tiered referral in the treatment of patients with TB spondylitis in the community.

#### **V. References**

- [1]. Adelman RD, et al (2015). Caregiver Burden A Clinical Review. JAMA March 12, 2014 Volume 311, Number 10. Downloaded From: <http://jama.jamanetwork.com/> by aTel-Aviv University User on 10/17 / 2015.
- [2]. Alligood. ( 2014 ). Experts Theory Nursing and Creation They. Elsevier : Jakarta.
- [3]. Alavi and Sharifi. (2010). Tuberculous Spondylitis: Risk factors and clinical /paraclinical aspects of the south west of Iran. 1876-0341 / \$ - see frontmatter © 2010 King Saud Bin Abdul aziz University for Health Sciences. Published by Elsevier Ltd. All rights reserved.doi: 10.101/j.jiph.2010.09.005.
- [4]. Arikunto S, (2006). Research Procedures A Practice Approach . Ed Revision VI, Jakarta: Publisher PT Rineka Cipta
- [5]. Bursch, HC, & B, HK, (2012). Caregivers' Deepest Feelings in Living with Alzheimer's Disease. Received: January 18,2011; Accepted: August 19, 2011; Posted: June 15, 2012. Doi: 10.3928 / 19404921-20120605-03
- [6]. B ex, T. (2016). Walking on eggshells: The lived experience of partners of veterans with PTSD. The Qualitative Report, 21 (4), 645-660. Retrieved from <http://nsuworks.nova.edu/tqr/vol21/iss4/4>
- [7]. Colaizzi, P. E. ( 1978 ) . Psychological research as the phenomenologist views it . In: Valle, RS, King, M. (Eds.), Existential phenomenological Alternatives for Psychology. Oxford University Press, New York, pp. 48-71 .
- [8]. Creswell, JW (2010). Research Design. Approach Qualitative, Kuantitatif and Mixed. Third Edition. Jakarta: Library Learning.
- [9]. Ching-Yun Weng, Mao-Wang Ho., Et al . (2010). Spinal Tuberculosis in Non-HIV-Infection Patient: 10 Year Experience of a Medical Center in Central Taiwan. 2010 Taiwan Society of Microbiology. Published by Elsevier Taiwan LLC.
- [10]. Denzin, NK & Lincoln, YS (2008). Handbook of Qualitative Research . Yogyakarta: Student Literature
- [11]. Emanuel EJ , MD, PhD; Diane L. Fairclough, DPH; Julia Slutsmann, B A; and Linda L. Emanuel, MD, PhD. (2016). Understanding Economic and Other Burdens of Terminal Illness: The Experience of Patients and Their Caregivers. 2000 American College of Physicians-American Society of Internal Medicine. Downloaded From: <http://annals.org/> by a Penn State University Hershey User on 05/11/2016 .



- [12]. Eisen , et al., (2012). Spinal tuberculosis in children. *Arch Dis Child* 2012; 97: 724-729. doi: 10.1136 / archdischild-2011-301571. Received 19 December 2011 Accepted 18 May 2012. Published Online First 25 June 2012.
- [13]. E. Kristi Poerwandari, (1998). *Qualitative Approach in Psychological Research* . LPSP3. Faculty of Psychology. University of Indonesia. Jakarta
- [14]. Giorgi, A . ( 2000 ) . Concerning The Aplication of Phenomenology to Caring Research. *Scandinavian Journal of Caring Science*.
- [15]. Giorgi, A., ( 2005 ) . The phenomenological movement andresearch in the humansciences . *Nursing Science Quarterly*18 (1), 75-82.
- [16]. Giorgi, A. (2011). *IPA and Science: A Response to Jonathan Smith* . *Journal Of Phenomenological Pshycology*.
- [17]. Public Relations RSHS. (2014). *Spinal TB, Paint Being a Preliminary Detection* . Downloaded on January 20, 2017. <http://web.rshs.or.id/tb-tulang-belakang-nyeri-menjadi-awal-deteksi/>
- [18]. Paramarta , IGA , Purniti, PS, Subanada, IB, Astawa , P. (2008).
- [19]. *Tuberculosis Spondylitis* . *Sari Pediatri*, Vol. 10, No. 3, October 2008.
- [20]. Juniarti N & Evans D. (2010). A qualitative review: the stigma of tuberculosis . *Blackwell Publishing Ltd, Journal of Clinical Nursing*, 20, 1961-1970 doi: 10.111 / j.1365-2702.2010.03516.x
- [21]. Kim, et al . (2016). Safety of Resuming Tumor Necrosis Factor Inhibitors in Ankylosing Spondylitis Patients Concomitant with the Treatment of Active Tuberculosis: A Retrospective Nation wide Registry of the Korean Society of Spondyloarthritis Research . *PLOS ONE* | DOI : 10.1371 / journal.pone. 0153816 April 21, 2016
- [22]. Maxed, et al . (2014). An Exploration of the Experience of Huntington's Disease in Family Dyads: An Interpretative Phenomenological Analysis . *J Genet Counsel* (2014) 23: 339-349 . DOI 10.1007 / s10897-013-9666-3 . Received: 11 March 2013 / Accepted: 27 October 2013 / Published online: November 10, 2013 . National Society of Genetic Counselors, Inc. 2013 .
- [23]. Miller, et al . (2016). Support for Living a Meaningful Life with Osteoarthritis: A Patient-to-Patient Research Study . *Patient* (2016) 9: 457-464 DOI 10.1007 / s40271-016-0169-9 . Published online: April 16, 2016 Springer International Publishing Switzerland 2016
- [24]. Moloeng, MA, Lexy J. (2013). *Methodology Research Qualitative*. Revised Edition. Bandung: Rosdakarya.
- [25]. Mubarak, WI Chayatin, NBA (2011). *Community Nursing Concept and Application*, Jakarta: Salemba Medika
- [26]. Polit & Beck . ( 2008 ) . *Nursing Research: Generating And Asesing Evidence for Nursing Practice*. Eight Edition. Lippincott Williams & Wilkins.
- [27]. Probst S., et al . (2012). Caring for a loved one with a malignant fungating wound . *Support Care Cancer* (2012) 20: 3065-3070 DOI 10.1007 / s00520-012-1430-y . Received: 25 March 2011 / Accepted: 27 February 2012 / Published online: 6 March 2012 . Springer-Verlag 2012
- [28]. Rhee , SR , et al. (2008). Depression in Family Caregivers of Cancer Patients: The Feeling of Burden As a Predictor of Depression. by American Society of Clinical Oncology . Downloaded from [ascopubs.org](http://ascopubs.org) by 114.120.238.171 on March 8, 2017 from114.120.238.171.
- [29]. Shi, et al ., (2016). Retrospective Study of 967 Patients With Spinal Tuberculosis . Received: December 3, 2015; Accepted: March 28, 2016. doi: 10.3928 / 01477447-20160509-03
- [30]. Sugiono. (2009). *Quantitative research methods, Qualitative and R & D* .Bandung: Alfabeta
- [31]. Sukumani, JT, Lebesse, RT, Khoza, LB, Risenga, PR (2012). Experiences of Family Member Caring for Tuberculosis Patients at home at Vhembe District of The Limpopo Province. Doi : 10.4102 / curationis.v35i1.54. Received: September 02, 2011; Accepted: Feb 28, 2012
- [32]. Tao Shi, MD; JianzhongXu, MD et al . (2016). Retrospective Study of 967 Patients With Spinal Tuberculosis. doi: 10.3928 / 01477447- 20160509 -03. Received: december 3.2015; Accepted: March 28, 2016.
- [33]. Van Manen, M., ( 1997 ) . *Researching the lived experience: humanscience for an action sensitive pedagogy* , second ed.Althouse Press, Ontario.
- [34]. Yu & He, (2016). Surgical treatment for lumbar tuberculosis by posterior transforaminal lumbar debridement, interbody fusion, and instrumentation in the aged.*SpringerPlus* (2016) 5: 615 DOI 10.1186 / s40064-016-2243-0.

- [35]. Weng, et al ., (2010). Spinal Tuberculosis in Non-HIV-Infected Patients: 10 Year Experience of a Medical Center in Central Taiwan . *A Microbiol Immunol Infect* 2010; 43 (6): 464-469. Journal homepage : <http://www.e-jmii.com> .
- [36]. <http://www.tbindonesia.or.id/tb-mdr/>