

Research Article

Reconstruction of Social Support Approach Model for Tuberculosis Patients

ABD. HADY J¹, ANDI AGUSTANG², ARLIN ADAM³, HARIANI⁴, AMBO UPE⁵, INDAH AINUN MUTIARA⁶

¹Universitas Negeri Makassar, Indonesia.

²Universitas Negeri Makassar, Indonesia.

³Universitas Negeri Makassar, Indonesia.

⁴Politeknik Kesehatan Makassar, Indonesia.

⁵Department of Sociology, Halu Oleo University, Kendari, Indonesia.

⁶Universitas Muhammadiyah Makassar, Indonesia.

Email: hadi3junaidi@gmail.com¹, andiagust63@gmail.com², arlin.adam73@gmail.com³

harianicecant01@gmail.com⁴, ambo.upe@uho.ac.id⁵, indahainun@unismuh.ac.id⁶

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ABSTRACT

This study aims to determine the reconstruction of the social support approach for tuberculosis patients' healing process. Methodologically, this research is based on a phenomenological approach. The results showed the reconstruction of the social support approach model needed to solve the internal and external problems is: (1) Maintain the paradigm and social belief that social support is an integral part of the system of treatment and cure of tuberculosis disease, (2) Promote an openness to all traits, types and forms of social support in a reciprocal way, (3) Development of mutual assistance based on local cultural wisdom values and socio-cultural norms in social support approach, (4) Empowerment of social competences in developing methods and strategies for innovative and creative social support approaches in accordance with the characteristics and needs of social support, (5) Institutionalization of social support into a social system and social structure, belief tradition system, system of values of local cultural wisdom, system of socio-cultural norms, medical service system, as well as government policy systems and programs in the prevention of tuberculosis disease, (6) Institutionalization of potential social support sources in an integrated and comprehensive, (7) Development of policies and programs specifically for social support approaches, (8) Institutionalization of participation of all parties both tuberculosis patients, family, neighbors, colleagues, social workers, health cadres, medical personnel, as well as other stakeholders, (9) Development of more specific macro-micro design to solve every problem of social support needs, (10) Development of social support approach strategies in an integrated and comprehensive manner to the problems faced by tuberculosis patients and its families.

Keywords: Approach Model, Social Support, Tuberculosis Disease.

INTRODUCTION

Generally experts and observers of health problems and diseases such as Busfield (1988), Conrad & Kern (1990), Rich et al. (2000) and others agreed to consider that disease is not only a cultural product but also a social construct. In that regard, Geest and Whyte (2012) suggests that in different communities diseases are expressed differently, explained differently, and constructed differently. Furthermore, one type of disease that has not only caused health problems but has also become a social problem is widely known as tuberculosis. Tuberculosis disease according to international health institutions (WHO) and national (Ministry of Health) is equivalent and included in ten types of deadly diseases in the world such as AIDS/HIV, cancer, malaria, as well as degenerative diseases such as heart and diabetes that have the nature, potential

and level of ability to attack the organs of the human body deadly. Tb disease has become a global health problem because it has deadly properties if it attacks the organs of the human body, especially the lungs.

According to the WHO, every second there is one person infected with tuberculosis in the world: a third of the world's population has been infected with tuberculosis germs; about 33% of the total cases of tuberculosis in the world are found in Asian countries. In 2013, there were an estimated 8.6 million tuberculosis cases of 1.1 million people (13%) tuberculosis with HIV positive (WHO, 2014). Tuberculosis disease is one of the highest causes of death from infection in the world, in addition to malaria, and with its dangerous nature has become a global health problem and received a lot of attention from the international community because in addition to

affecting the productivity of people's work is also the leading cause of death of many people in various countries. WHO reports that half a percent of the world's population suffers from tuberculosis, mostly (75%) in developing countries including Indonesia. Each year an estimated 539,000 new cases of tuberculosis are found with 101,000 deaths (WHO, 2014).

Tuberculosis is still the world's leading health problem, causing health problems for millions of people each year and an estimated 10.4 million cases of tuberculosis in the world account for about 5.9 million cases of men, and about 3.5 million cases of women (WHO, 2017), and Indonesia has accounted for one-third of the world's tuberculosis burden (WHO, 2017). Indonesia is one of the countries with the largest tuberculosis burden among 8 countries, namely India (27%), China (9%), Indonesia (8%), Philippines (6%), Pakistan (5%), Nigeria (4%), Bangladesh (4%) and South Africa (3%). According to a 2018 WHO report, globally 6.4 million new cases of tuberculosis, and equivalent to 64% of tuberculosis incidence (10.0 million).

Tuberculosis remains the 10 highest cause of death in the world and tuberculosis deaths globally are estimated at 1.3 million patients (WHO, 2018). A country that is not yet free from tuberculosis then the death rate due to germs mycobacterium tuberculosis is getting higher. Therefore, tuberculosis is still an infectious disease that is an important public health concern and problem in the world (Marks, et al., 2013; Garcia-Basteiro, et al., 2018). Especially in Indonesia, it is still one of the countries that belong to the group with the largest burden of TB problems (high burden countries). It has also been confirmed by who's report that Indonesia is included in the 30 high burden countries that have the burden of TB, TB-MDR and TB-HIV (WHO, 2017). According to the Ministry of Health, in 2017 there were 446,732 cases, and increased to 566,623 cases in 2018 in all provinces. In each province, men generally have a higher number of tuberculosis cases which is 1.3 times than women (Kemenkes RI, 2019).

Furthermore, in terms of age group, Tb disease affects all age groups ranging from toddlers to the elderly. In other words, TB sufferers are at all levels or levels of age. For the last four years (2014-2018) for example, TB disease or TB patients are distributed evenly in all age groups although the proportion of cases varies or varies/ varies. In 2018, the most tuberculosis cases in the 45-54 age groups were 14.2%, then 13.8% of the 25-34 year old age group and 13.4% of the 35-44 age groups. The Ministry of Health conducts a sweep of cases in hospitals (Mapping Up) to

reduce under reporting of tuberculosis cases, and the data of the combing results include groupings of unknown age groups (NA) resulting in a shift in the proportion of tuberculosis cases based on the age group of year 2014-2017 with Year 2018. In short, Indonesia is still one of the countries that belong to the group with the largest burden of TB problems (Directorate General of P2P, Ministry of Health, 2019).

Specifically in South Sulawesi, there were 13,659 TB cases consisting of 12,965 TB cases (7,180 cases of Positive BTA TB), 97 cases of MDR TB and 597 cases of TB in children with positive BTA TB (South Sulawesi Provincial Health Office, 2018). South Sulawesi still has 84.0% of CDR cases or is ranked second highest after DKI Jakarta. In addition, it is also still classified as the area with the second highest CNR figure (after DKI Jakarta) for all cases of tuberculosis (per 100,000 inhabitants) (Kemenkes RI, 2019).

All of these data clearly indicate that South Sulawesi is still a place of thriving tuberculosis. The high prevalence of the TB population suggests that tackling TB requires an extra approach socially beyond the medical-only approach. Although the Government, especially the Ministry of Health has adopted who's recommendations on the implementation of the Directly Observed Treatment Short-course (DOTS) strategy since 1995 as an approach in tackling TB (Ministry of Health, 2012) and established PERMENKES No. 67 Year 2014 on Tuberculosis Prevention by launching the TOSS (Find Cure Until Cured) TB program in the hope that Indonesia will be free from this disease before 2050, but the policies and programs are not adequate because it is more dominant only concerning the issue of medical treatment support alone, and very far does not touch the aspect of social support needs as a whole. Therefore, tuberculosis management and healing of the patient's subjects are in desperate need of the presence and synergy of medical and non-medical approaches, especially social support.

METHODS

This research is based on or based on the paradigm of constructivism, which is a paradigm that is interpretative, logical and aesthetic in studying an issue (Bodgan & Taylor, 1984; Lee, 2012; Kamal, 2019). The method of approach with research specifications is a combination of descriptive analytical, inferential, componential (Seidman, 2006; Asaka & Awarun, 2020). The research approach used is qualitative with case studies (Yin, 2014). The key informants of this study included tuberculosis patients, family, neighbors, colleagues, and social workers. Data

collection techniques with literature studies, observations, interviews (Morgan & Harmon, 2001). The process of data analysis is carried out through stages, namely identification according to the research objectives group, processing and interpreting the data and then abstraction, reduction and checking the validity of the data. The stages of data analysis in qualitative research are data reduction, data display, and conclusion or verification (Miles & Huberman, 1984; Creswell, 1998).

RESULTS AND DISCUSSION

Social Problems Faced by Tuberculosis Patients and Nearby People

Based on the results of the study, in general, various problems faced by tuberculosis patients can be classified into two large components, namely internal and external. First, internal problems consist of (1) physical problems such as impaired gestures and difficulty performing physical activity, (2) psychic problems such as mental instability and emotional disorders, emotions are so fickle that they are easily offended and angry, stress and depression, frustration, feelings of sadness and anxiety, (3) lifestyle and health behavior problems and bio-cultural such as lazy treatment, feeling saturated and tired of taking medication, lazy health control, and food problems, (4) social problems such as over sensitiveness, suspicion and skepticism in others, (5) cultural problems such as lack of handle and philosophical principles of life, weak religious faith and belief values, (6) economic problems such as decreased work productivity, inability to work, loss of livelihood and employment.

Second, external problems consist of (1) physical problems such as difficulty working and work taken over by others, (2) psychic problems such as negative perceptions of tuberculosis patients, (3) problems of health and biological behaviors such as unchanging and bad, unhealthy habit patterns of those around them, limited stock of medicines, health servants, medical personnel, and nutritious food, (4) social problems such as social relationships, poor and negative perceptions of others towards tuberculosis patients, social discrimination and conflict, labeling, exclusion, and stereotype, (5) cultural problems such as the still existing assumption from others around that Tb disease is a curse, witchcraft, karma, neglect of local cultural wisdom values and socio-cultural norms by people around in providing support, (6) economic problems such as dismiss tuberculosis patients from his work as a worker, difficulty obtaining a job, lack of material and financial assistance from

others, (7) political problems such as ignorance among tuberculosis patients and those close to him regarding the implementation of Government policies and programs related to DOTS/TOSS in the prevention of TB disease, inequality of information about free drug services, inequality of providing assistance to tuberculosis patients and his family.

Various internal and external problems are a strong and fundamental reason to organize social support for tuberculosis patients. This is in line with Baron and Byrne's opinion (2000) that social support arises by the perception that there are people who will help in the event of a situation or event that is seen to cause problems and that assistance is felt to increase positive feelings and increase self-esteem. This psychological condition or state can affect individual responses and behaviors so that it affects the well-being of the individual in general. Similarly, Piece (Baron and Byrne, 2000) argues that social support as an emotional, informational or mentoring resource provided by people around the individual to deal with every problem and crisis that occurs every day in life, or as stated by Cohen and Wills (Baron and Byrne, 2000) that social support is needed as a help and support that a person obtains from his interactions with others.

The opinion on the need for social support is also in accordance with the stated by Uchino (2014), Chappell & Funk (2011) that social support as one of the functions of social relations that describes the level and general quality of interpersonal relationships that will protect individuals from the consequences of stress. Social support received can make individuals feel calm, cared for, confident and competent. The availability of social support will make individuals feel loved, valued and part of the group (Smet, 1994). According to Taylor (2009), social support as information received from others that the individual is loved, cared for, has self-esteem and value and is part of a network of communication and mutual obligations that means mutual need obtained from parents, husbands, or loved ones, family, friends, social relations and communication (Taylor, 2009). Baron and Byrne (2000) viewed social support as a physical and psychological comfort provided by individual friends and family. Similarly, Cobb stated that social support is a comfort, attention, appreciation, or assistance felt by individuals from other people or groups (Baron and Byrne, 2000).

Construction of Social Support

The Patient's Perspective

As a recipient center for social support (informational, emotional, instrumental, rewarding), tuberculosis patients constructs eight

main aspects of social support. First, tuberculosis patients' constructs the paradigm that social support as a drug, or an integral part of the process of treatment and healing of diseases suffered. Second, tuberculosis patients' constructs its level of importance that social support is already a primary need for self and the disease it suffers both from itself and from others, especially those close to it. Third, tuberculosis patients' constructs its own social condition and its need for social support (informational, emotional, instrumental, appreciation), with certain similarities and differences between the tuberculosis patients'.

Fourth, tuberculosis patients' constructs sources of social support (informational, emotional, instrumental, appreciation) from people close to him, especially family (spouses, close relatives), parents, neighbors, friends, and medical personnel. In this context, the SPP Tb also constructs the similarities and differences of elimination, dichotomy, clusters and classifications or groupings of actors-social agents of families and communities that are considered the most important and influential in certain social support, even giving birth to the construction of "central social figures" from the social actors of the family and society.

Fifth, SPP Tb constructs similarities and differences in characteristics, traits, types and forms and indicators of certain social support received from people close to him (especially family (spouses, close relatives), parents, neighbors, friends, and medical). Sixth, SPP Tb constructs similarities and differences in assessment of attitudes, actions and social behaviors as well as approach methods used by people close to them in providing social support (informational, emotional, instrumental, appreciation).

Seventh, SPP Tb constructs similarities and differences in attitudes, actions and social behaviors as well as its approach methods in responding to social support (informational, emotional, instrumental, appreciation) of people close to it. Eighth, SPP Tb constructs the same and different perceptions of the existence and absence of internal and external conflicts, social discrimination, label, stigma, stereotypes, and social expression of people around him.

The research findings are in line with the findings of Gyimah & Dako-Gyeke (2019) which concluded that personal patient-related challenges and health system bottlenecks were major influencing factors in providing care and support to TB clients. Likewise with the findings of De Souza Neves, et al (2018) that social support can reduce the negative consequences of TB

disease which directly affect the quality of life of patients.

The Social Agent Perspective

The actors-social agents of families and communities in the study generally constructed twelve main aspects in connection with its position as providing social support (informational, emotional, instrumental, appreciation) to SPP Tb. The twelve main aspects are: First, Constructing the same paradigm that social support as a drug, or an integral part of the process of treatment and healing of diseases suffered by SPP Tb; Second, Construct the same assessment that social support is already a primary need for SPP Tb; Third, Construct the same assessment, social feelings and awareness and social responsibility that they feel the need to intervene involved in taking a direct or indirect role to meet the primary needs of social support for the SPP Tb; Fourth, Construct the same and different assessments of the social conditions (informational, emotional, instrumental, appreciation) of SPP Tb; Fifth, Construct the same and different assessments regarding the attitudes, actions and social behaviors (STP) of SPP Tb to their respective social support conditions; Sixth, Construct the same and different attitudes, actions and social behaviors (STP) in meeting the needs of social support (informational, emotional, instrumental, appreciation) of each SPP Tb; Seventh, Construct the same and different ways or methods of approach, innovation, creativity and social competencies in overcoming problems and meeting the needs of social support (informational, emotional, instrumental, appreciation) of each SPP Tb; Eighth, Constructing the application of local cultural wisdom values and socio-cultural norms that are equal and different in the provision and fulfillment of social support needs of each SPP Tb; Ninth, Construct the performance of social relations of family culture, kinship, friendship and different in the provision and fulfillment of social support needs of each SPP Tb; Tenth, Construct the same and different assessments, attitudes, responses, actions and social behaviors towards social support (informational, emotional, instrumental, appreciation) of others to each SPP Tb; Eleventh, Construct the same and different perceptions, attitudes, actions and social behaviors regarding the existence and absence of internal and external conflicts, social discrimination, label, stigma, stereotypes, social expression against SPP Tb from those around it; Twelfth, Constructing the influencing factors (supporters and inhibitors, strengths and weaknesses) of social support. The twelve main aspects form a construction model of social

support for family and community social agents towards SPP Tb.

Strengths and Weaknesses in Social Support Development

Based on the results of research and analysis, there are a number of potential social forces in the approach of social support development for SPP Tb, namely (1) Potential Values of local cultural wisdom, (2) Potential social norms of families and communities, (3) Potential types of social support, (4) Potential social relationships of family and community behavior, (5) Potential lifestyle changes, (6) Potential positive perceptions of families and communities, (7) Potential information and socialization of health/medical, (8) Potential social impacts of Tb disease positively, (9) Potential policies (DOTS or TOSS programs). While the potential social weaknesses in the approach of social support development of SPP Tb are (1) Potential Shifts and abandonment of local cultural wisdom values, (2) Potential abandonment of socio-cultural norms of families and communities, (3) Potential abandonment of social support, (4) Potential neglect of social relations (kinship, brotherhood, friendship) in the social behavior of families and communities, (5) Potential lifestyle status quo, (6) Potential negative perception of SPP Tb, family, and society, (7) Potential stereotypes, stigma-labelling, (8) Potential social discrimination and conflict, (9) Potential social expression of sufferer subjects, (10) Potential information gaps and medical socialization, (11) Potential negative impacts of Tb disease, (12) Potential inequality of policy implementation/DOTS/ TOSS programs.

Reconstruction of Social Support Approach Model for Tuberculosis Patients

Reconstruction of social support model from SPP Tb perspective

Based on the results of research and analysis on the construction of social support SPP Tb, then there are eight main aspects that require the reconstruction of social support from the perspective of SPP, namely:

- 1) Reconstruction of the paradigm of SPP in order to continue to view and place social support as a medicine, or an integral part of the process of treatment and healing of diseases suffered;
- 2) Reconstruction of the importance of SPP in order to continue to require the placement of social support as a primary need for themselves and the diseases suffered both from themselves and from others, especially those close to them;
- 3) Reconstruction of social conditions and SPP needs for social support (informational, emotional, instrumental, appreciation) according to its characteristics;

- 4) Reconstruction of SPP assessment that eliminates, dichotomizes, radicalizes and fragments the role of actors-social agents of families and communities of nearby people (family (spouses, close relatives), parents, neighbors, friends, and medical personnel) as a source of social support (informational, emotional, instrumental, appreciation) into the construction of certain "central social figures";
- 5) Reconstruction of differences in characteristics, traits, types and forms and indicators of certain social support received from people close to them (especially families (spouses, close relatives), parents, neighbors, friends, and medical personnel);
- 6) Reconstruction of differences in SPP assessment of social attitudes, actions and behaviors and approach methods used by people close to them in providing social support (informational, emotional, instrumental, appreciation);
- 7) Reconstruction of differences in attitudes, actions and social behaviors as well as SPP approach methods in responding to social support (informational, emotional, instrumental, appreciation) of those close to them;
- 8) Reconstruction of negative perception of SPP, internal and external conflict, social discrimination, label, stigma, stereotype, social expression of those around it.
 - a. Reconstruction of the social support model from the perspective of actors-social agents of families and communities.

Based on the results of research and analysis on the construction of social support, there are twelve main aspects that require the reconstruction of social support from the perspective of those close to them (actors-social agents of families and communities), namely:

- 1) Reconstruction of paradigms actors-social agents of families and communities in order to continue to view and place social support as a medicine, or an integral part of the process of treatment and healing of SPP disease;
- 2) Reconstruction of the assessment of family and community social actors to continue to view and place social support as a primary need for SPP;
- 3) Reconstruction of assessment, social feelings and awareness and social responsibility of family and community social agents so that they still feel the need to intervene involved in taking a direct or indirect role to meet the primary needs of social support for SPP;
- 4) Reconstruction of differences in assessment of family and community social actors to overcome inequality of social conditions

- (informational, emotional, instrumental, appreciation) of SPP;
- 5) Reconstruction of differences in the assessment of actors-agents of family and community social agents in overcoming problems and inequality of attitudes, actions and social behaviors (STP) SPP Tb to the condition of their respective social support;
 - 6) Reconstruction of differences in attitudes, actions and social behaviors (STP) of family and community social agents in meeting the needs of social support (informational, emotional, instrumental, appreciation) of each SPP;
 - 7) Reconstruction of different ways or methods of approach, innovation, creativity and social competence of actors-social agents of families and communities in overcoming problems and meeting the needs of social support (informational, emotional, instrumental, appreciation) of each SPP;
 - 8) Reconstruction of the role of family and community social actors in the application of local cultural wisdom values and socio-cultural norms for optimization and effectiveness of the provision and fulfillment of the needs of social support of each SPP;
 - 9) Reconstruction of the performance of social and cultural relationships of family, kinship, friendship actors-agents of family and community social agents to optimize and effectiveness of the provision and fulfillment of the needs of social support of each SPP;
 - 10) Reconstruction of differences in assessment, attitude, response, actions and social behavior of family and community social agents towards social support (informational, emotional, instrumental, appreciation) of others to each SPP;
 - 11) Reconstruction of differences in perceptions, attitudes, actions and social behaviors of family and community social agents to minimize internal and external conflicts, prevent the occurrence of social discrimination, label, stigma, stereotypes, social expression against SPP Tb from those around them;
 - 12) Reconstruction of inhibitory factors and weaknesses of social support of family and community social agents to SPP.
- b. Reconstruction of overall social support model (integrated and comprehensive)
- Based on points a and b, the steps in the model of reconstruction of social support needed include:
- 1) The SPP Tb and those close to it, especially families, parents, neighbors and friends need to have and maintain the paradigm and social belief that social support is a drug, or an integral part of the system of treatment and healing of diseases suffered by SPP;
 - 2) The SPP Tb need to put forward an attitude of openness to all traits, types and forms of social support from those around them;
 - 3) The actors-agents of social families, jobs, medical services and the community need to develop a tradition of mutual cooperation based on the values of local cultural wisdom and socio-cultural norms in the development of social support approaches to SPP Tb;
 - 4) The actors-agents of social families, jobs, medical services and communities need to have social competencies and develop methods and strategies of social support approaches to innovative SPP Tb, creative, distinctive, unique, and special in accordance with the characteristics and needs of social support for SPP Tb;
 - 5) Social support needs to be institutionalized into a social system and social structure, tradition system of belief, system of values of local cultural wisdom, system of socio-cultural norms, medical service system, and government policy system and programs in the prevention of Tb disease;
 - 6) The actors-agents of social families, jobs, medical services and communities need to be positioned as a potential source of social support for SPP Tb, and at the same time need to be institutionalized into a social support system for SPP Tb in an integrated, comprehensive and comprehensive manner;
 - 7) The development of social support approaches requires policies and programs of empowerment of SPP Tb, and actors-agents of social families, jobs, medical services and communities in order to more effectively achieve their goals and objectives;
 - 8) Reconstruction of social support approach for SPP Tb requires participation and social participation of all parties and social institutions both SPP, families, parents, neighbors, friends, colleagues, social workers, health cadres, medical personnel, NGO activists, community elites, government political elites, experts and social practitioners, as well as other stakeholders;
 - 9) Reconstruction of social support approach requires a more specific macro-micro design to solve every problem of social support needs (informational, emotional, instrumental, appreciation) SPP Tb so that the provision of social support becomes appropriate, targeted and effective;
 - 10) Reconstruction of social support approach requires an integrated, comprehensive and

comprehensive strategy on the problems faced by SPP Tb and his family.

c. Reconstruction of social support component theory

There are many concepts and theories regarding the components of social support that are expressed by various experts such as informational support, emotional support, instrumental support, award support, material support, friendship support, social network support, and so on. But all these concepts and theories are less effective in meeting the needs of various internal and external problems faced by the SPP, and those close to it. Therefore, the author proposes a reconstruction of the concepts and theories of social support components in other formats in accordance with the conditions of internal and external problems, namely (1) socio-physical support (motion activities), (2) socio-psychological support (attention, empathy, caring, emotional, mind, mental, psychiatric, appreciation), (3) socio-medical support (medical services, medications, changes in lifestyle patterns, healthy lifestyle behaviors, health protocols), (3) socio-bio-cultural support (nutritious food, balanced menu, functional food), (4) socio-integration support (paradigms and social beliefs, social needs, attitudes, actions, social behaviors, motivation, positive perception, social interaction, socialization, education, empowerment, communication, information), (5) socio-cultural support (values of local cultural wisdom, socio-cultural norms), (6) socio-cultural support (ideology, spiritual, social worship), (7) socioeconomic support (livelihood, employment, income, finance, materials, facilities), (8) socioeconomic support (entertainment, tourism, recreation), (9) sociopolitical support (knowledge and access to government policies and programs), rights to public-medical service assistance policies and programs), (10) socio-legal support (legal protection of human rights and dignity, knowledge of legal and ethical norms).

CONCLUSION

Reconstruction of social support approach models needed to overcome internal and external problems are: (1) Maintaining the paradigm and social belief that social support is a drug, or an integral part of the system of treatment and cure of Tb disease, (2) Promoting an attitude of openness to all traits, types and forms of social support in a reciprocal way, (3) Development of mutual assistance based on local cultural wisdom values and socio-cultural norms in social support approach, (4) Empowerment of social competence in the development of innovative, creative, distinctive, unique, and special social

support approach methods and strategies in accordance with the characteristics and needs of social support, (5) Institutionalization of social support into a social system and social structure, belief tradition system, system of values of local cultural wisdom, system of socio-cultural norms, medical service system, as well as government policy systems and programs in the prevention of Tb disease, (6) Institutionalization of potential sources of social support in an integrated, comprehensive and comprehensive manner, (7) Development of policies and programs specifically approaching social support, (8) Institutionalization of participation and social participation of all parties and social institutions both SPP, families, parents, neighbors, friends, colleagues, social workers, health cadres, medical personnel, NGO activists, community elites, government political elites, experts and social practitioners, as well as other stakeholders, (9) Development of macro-micro design that is more specific to solve every problem of social support needs, (10) Development of strategies for integrated, comprehensive and comprehensive approach to social support problems faced by SPP Tb and its families.

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