

## **The Stages Of Community Organization Based On Tuberculosis Survivors In Jember Regency**

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**Abstract:** *This research investigates the stages of organizing tuberculosis survivor-based communities in Jember Regency. Drug-resistant tuberculosis (DR-TB) survivors possess empathy and a sense of urgency due to their personal experiences with the impact of DR-TB. These survivors have established a community-based organization to support DR-TB patients. This study employs a qualitative approach using Basic Research with a cross-sectional time dimension. The location was determined using purposive area sampling. Research informants are categorized into two groups: primary informants (chairperson, representative, and treasurer) and additional informants (DR-TB patients). Data collection techniques included non-participatory observations, semi-structured interviews, and documentation. The findings of this study indicate that the eight stages of organizing Sekawan's TB community significantly enhance the quality and capacity of community resources, expand the community's presence, and build trust among the public and stakeholders. Moreover, the community's efforts effectively reduce stigma and discrimination against patients, improve patient welfare and recovery rates, and serve as a source of education and support for patients and their families.*

**Keywords:** *Community Based Organization, Community Organizing, Drug Resistant, Survivor Based Community, Tuberculosis.*

**Abstrak:** *Penelitian ini tentang tahapan pengorganisasian komunitas berbasis penyintas Tuberculosis di Kabupaten Jember. Penyintas Tuberculosis resisten obat memiliki empati dan perasaan senasib karena pernah mengalami dampak TB-RO. Penyintas TB-RO membentuk komunitas berbasis penyintas untuk mendampingi pasien TB-RO. Penelitian ini menggunakan pendekatan kualitatif dengan jenis penelitian Basic Research dimensi waktu cross sectional. Teknik penentuan lokasi menggunakan teknik purposive area. Informan penelitian dibagi menjadi dua, yakni informan pokok (ketua, wakil, dan bendahara) dan informan tambahan (pasien TB-RO), dengan teknik pengumpulan data melalui observasi non partisipatif, wawancara semi terstruktur, dan dokumentasi. Hasil dari delapan tahapan pengorganisasian Sekawan's TB dapat meningkatkan kualitas dan kapasitas sumber daya dalam komunitas, mampu memperluas eksistensi, memperoleh kepercayaan dari masyarakat dan stakeholder, mengurangi stigma dan diskriminasi yang diterima pasien, meningkatkan kesejahteraan dan angka kesembuhan pasien, serta menjadi sumber edukasi dan dukungan bagi pasien dan keluarganya.*

**Kata kunci:** *Community Based Organization, Komunitas Berbasis Penyintas, Pengorganisasian Komunitas, Resisten Obat, Tuberculosis.*

## 1. Introduction

In 2022, tuberculosis (TB) emerged as the second leading cause of mortality worldwide, surpassed only by COVID-19, and accounted for nearly twice the number of deaths attributed to HIV/AIDS (WHO, 2023). The World Health Organization (WHO) and United Nations (UN) member states have established the year 2030 as the target for eradicating the global TB epidemic (WHO, 2023). Although significant progress was observed in 2022 following disruptions induced by the COVID-19 pandemic, TB continues to represent a critical public health challenge. Indonesia is the second-largest contributor to global TB cases, recording 821,200 cases in 2023 (TB Indonesia, 2024). Within Indonesia, the highest incidence rates are concentrated in regions on Java Island, including DKI Jakarta, West Java, East Java, and Central Java (Ministry of Health, 2022). East Java ranks as the third-largest TB hotspot in the country, reporting 43,268 cases in 2021 (East Java Health Office, 2022). Among its regencies, Jember exhibits a particularly high prevalence, recording 2,918 cases in 2021, positioning it as the second-highest contributor to TB cases in the province, following Surabaya (BPS, 2022). This epidemiological burden has prompted the Jember Regency government to prioritize initiatives aimed at accelerating TB elimination efforts.

To address this public health concern, the local government in Jember has implemented a multifaceted approach. Measures include comprehensive TB screening, community engagement through collaborations with local organizations, support programs for TB and drug-resistant TB (TB-RO) patients facilitated by health cadres, targeted screenings for malnourished children with TB, awareness campaigns utilizing social media platforms, provision of free treatment at public health centers, and the establishment of a TB elimination acceleration task force.

One notable initiative in Jember is the Sekawan's TB community, founded in 2016 to specifically address the needs of TB-RO patients. This community, composed predominantly of TB-RO survivors, was the first support organization of its kind in Jember. Subsequently, other foundations, such as the Bhanu Yasa Sejahtera Foundation (Yabhysa), were established in 2020 to address the broader spectrum of TB-related challenges, including both drug-sensitive and drug-resistant TB. This research centers on Sekawan's TB due to its unique focus on survivor-based advocacy and support for TB-RO patients.

Sekawan's TB emerged from the profound empathy and shared experiences of its founder, who, as a TB-RO survivor, recognized the multifaceted challenges faced by affected individuals. The organization operates as a Community-Based Organization (CBO) under the supervision of several prominent entities, including the Koninklijke Nederlandse Centrale Vereniging tot bestrijding der Tuberculose (KNCV), the Indonesian Patient Organization Association (POP TB), and the Jember Health Office. Sekawan's TB is actively engaged in advocacy, education, and psychosocial support for TB-RO patients, addressing critical issues such as managing severe medication side effects, countering stigma within familial and

societal contexts, and promoting adherence to treatment protocols. These efforts significantly contribute to governmental strategies aimed at reducing the incidence of TB-RO in Jember.

Preliminary observations of Sekawan's TB reveal several adverse impacts of TB-RO that motivated survivors to establish the community. These impacts are categorized as follows: (1) Health dimensions, Patients experience significant deterioration in physical function, including deformities, disabilities, and premature mortality; (2) Social dimensions, TB-RO disrupts daily activities, diminishes productivity, and subjects patients to discrimination; (3) Economic dimensions, Many patients face job loss, reduced income, and an inability to meet familial financial needs.

These consequences profoundly affect the psychological well-being of TB-RO patients, often manifesting as stress, depression, and other mental health challenges that, in severe cases, necessitate psychiatric intervention. Compounding these difficulties is a pervasive lack of education regarding TB among patients and their communities, which fosters stigmatization. As Courthwright and Turner (as cited in Endria, 2019) observe, stigma surrounding TB is rooted in perceptions that frame the disease as highly contagious, dangerous, and indicative of poverty and uncleanness.

The challenges encountered by TB-RO patients, as outlined above, present substantial barriers for Sekawan's TB in its mission to provide comprehensive patient support. The organization faces both internal and external constraints, including limited financial resources and human capital, which complicate its operational sustainability. Despite these adversities, Sekawan's TB has demonstrated remarkable resilience and unwavering commitment, maintaining its focus on the eradication of TB-RO within the Jember region.

In light of the community's steadfast dedication and enduring efforts, it becomes imperative to examine the organizational dynamics and strategic approaches that underpin Sekawan's TB. Investigating the processes through which this survivor-based organization sustains its activities and effectively supports TB-RO patients in Jember could yield valuable insights. Such an exploration not only highlights best practices but also offers a framework for replication by similar organizations aiming to address TB-RO and other public health challenges. Consequently, this research seeks to analyze and document the organizational development, methodologies, and strategic initiatives employed by Sekawan's TB, emphasizing its role as a model for community-based tuberculosis interventions in Jember Regency.

## 1.1 Method

This study adopts a qualitative research methodology, emphasizing the collection and analysis of non-numerical data to derive narrative and descriptive insights (Steven Dukeshire & Jennifer Thurlow, as cited in Sugiyono, 2017). It is classified as basic research with a cross-sectional time dimension. Basic research aims to expand scientific knowledge and theoretical

frameworks (Semiawan, 2010), while the cross-sectional design facilitates data collection at a single point in time, enabling an analysis of contemporary phenomena (Abduh et al., 2023). The research site was selected using the purposive area sampling method, a deliberate selection approach guided by specific research objectives and contextual relevance (Bungin, 2003).

The sampling of participants or data sources was similarly conducted through purposive sampling, wherein individuals or entities are chosen based on predefined criteria and their relevance to the study's focus (Sugiyono, 2017). Data collection is a pivotal component of the research process, designed to systematically gather relevant information (Sugiyono, 2017). This study employed three primary data collection techniques: non-participatory observation, semi-structured interviews, and documentation analysis. To ensure the integrity and reliability of the findings, data validity was assessed using established qualitative research criteria, including credibility, transferability, dependability, and confirmability. These measures collectively enhance the robustness and trustworthiness of the research outcomes.

## 2. Result and Discussion

### 2.1. Result

#### 2.1.1. Community Profile

Sekawan's TB is a volunteer-based organization in Jember Regency, comprising TB-RO survivors driven by empathy for patients still undergoing recovery. The community originated from the efforts of AZ, a TB-RO survivor in Jember, who initiated patient support with minimal resources. AZ, having previously engaged with a TB survivor organization in Malang and undergone training as a patient advocate, became the first TB-RO survivor in Jember to return and provide localized support for fellow patients.

The establishment of Sekawan's TB was facilitated through collaborative efforts involving key stakeholders, including the Deputy TB Supervisor of the Jember Health Office, who coordinated with local health officials to form a survivor-based community dedicated to TB patient support. Partnerships were established with health promoters from Jember Pulmonary Hospital, the hospital director, the Petir Community, and the KNCV Indonesia Foundation.

In 2016, these stakeholders organized a series of training sessions for 15 TB-RO survivors from Jember, who subsequently became the inaugural members of Sekawan's TB. Sponsored by KNCV and the Global Fund, the training spanned two weeks and was held at Hotel Aston Jember. The sessions featured facilitators from KNCV, the Rekat Community, the Jember Health Office, the Aisyiyah Foundation (now Yabhysa), and the Ministry of Health. Following the training, the leadership of Sekawan's TB was formalized through a voting process, with AZ elected as the community's head. AZ further institutionalized the organization by registering its name and legal status with Indonesia's Ministry of Law and Human Rights.

Initially, Sekawan's TB focused on recruiting TB-RO survivors due to their firsthand understanding of patient challenges. However, constraints in human resources for administrative and advocacy roles prompted the inclusion of non-survivor members. The

community also encouraged recovered patients to participate in its initiatives. Recruitment now leverages social media promotions and interviews, ensuring new members comprehend the voluntary nature of their roles and the organization's limited funding. Presently, Sekawan's TB consists of 15 members, including administrative staff.

In 2017, Sekawan's TB formalized its vision, mission, and objectives in its bylaws. The vision emphasizes achieving a TB-free Indonesia and eradicating TB-RO in Jember. The mission encompasses combating TB-RO, motivating patients to seek treatment, reducing stigma, fostering cross-sector collaborations, and enhancing public awareness about TB-RO. The organization's objectives include improving human resource performance, providing psychosocial support, mitigating stigma, expanding support networks, and disseminating information on TB and TB-RO.

Organizational responsibilities are divided between patient advocates and administrative staff. Initially, the community extended its services to neighboring regions, including Bondowoso, Banyuwangi, and Probolinggo. However, during the COVID-19 pandemic, operations were confined to Jember. Currently, Sekawan's TB supports approximately 100 TB-RO patients in coordination with over 40 health centers and clinics, with patient referrals directed to Soebandi Hospital. The community's headquarters is located at JL. Udang Windu No. 17, Mangli. Support activities are allocated based on health center jurisdictions and coordinated under AZ's leadership in collaboration with Yabhysa and the Jember Health Office.

The success of Sekawan's TB is evaluated through metrics such as patient recovery rates, the detection of new cases, and improvements in patient welfare, reflecting the alignment of the community's achievements with its overarching vision, mission, and goals.

### *2.1.2 Conditions of TB-RO Patients Assisted by Sekawan's TB*

TB-RO patients assisted by Sekawan's TB face multifaceted challenges shaped by immunity levels, lifestyle, and environmental factors. The side effects of TB-RO medications are diverse and range in severity, categorized as mild, moderate, or severe. Common side effects include nausea, vomiting, dizziness, skin darkening, fatigue, joint pain, gout, appetite loss, itching, vision and hearing impairments, digestive issues, tingling sensations, and cold sweats. These physical symptoms are frequently exacerbated by mental health struggles such as stress, depression, and behavioral disorders, which significantly disrupt patients' ability to maintain employment or engage in social activities.

The impact of severe side effects often extends beyond health, triggering life-altering consequences such as job loss and marital breakdown due to financial strain. Compounding these difficulties, some patients refuse treatment because of shame, fear, or lack of awareness about TB-RO. Additionally, patients frequently encounter stigma and discrimination within their families and communities, rooted in misconceptions about the disease. Myths that TB is caused by witchcraft or hereditary factors, curable only through traditional remedies,

perpetuate these negative perceptions. Symptoms such as coughing up blood and stress-induced nightmares reinforce these misconceptions, further isolating patients. False beliefs about transmission—such as TB spreading through casual contact or shared utensils—contribute to patients' social exclusion and can lead to treatment abandonment.

Treatment for TB-RO in Jember is centralized at Soebandi Hospital's TB-RO clinic. Patients undergo monthly check-ups, which include sputum tests, blood work, and overall health assessments. Medication is dispensed at the hospital, prepared by local health centers, and delivered to patients weekly. To avoid treatment failure or the need to restart therapy, patients must adhere to a strict daily medication schedule. The treatment duration for TB-RO can extend up to two years, demanding sustained commitment.

Despite these challenges, Sekawan's TB has become a beacon of hope for patients and their families. Its members emphasize creating strong, supportive relationships while prioritizing patient well-being. Patients and families often express deep gratitude for the community's assistance, recognizing the emotional and practical support that Sekawan's TB provides. While some patients initially resist both treatment and community involvement, persistent dialogues and compassionate advocacy frequently lead to a change in perspective, enabling patients to appreciate the valuable support and encouragement they receive.

### *2.1.3 Supporting Factors in Sekawan's TB*

Sekawan's TB benefits from a range of supporting factors that enable its operations and activities. Funding is a critical aspect, with contributions coming from POP TB, which finances initiatives such as Focus Group Discussions (FGDs) and provides essential medical supplies like N95 masks and hand sanitizers for TB-RO patients. Other key donors include organizations like YDSF and KNCV, which have provided financial support over a three-year period. During Regent Faida's administration, Sekawan's TB also secured regional budget (APBD) funding through the Jember Health Department. Additionally, individual donors contribute to sustaining the community's efforts.

Paid roles within Sekawan's TB are limited to specific positions such as the administrative coordinator and intern mentors. These salaries support tasks including mentoring interns, running the TB Army program, and assisting with vaccinations. Mentors also receive incentives for patient-related activities and contributions to the TB Army, reflecting the scope of their responsibilities.

Non-survivor human resources play a vital role, with support from interns affiliated with the Bakrie Foundation and university students. These contributors assist in various capacities, including educational outreach, FGDs, administrative work, social media management, and the distribution of basic necessities. Currently, four non-survivor members are actively involved in managing Sekawan's TB operations.

Another significant resource is a shelter home funded by the Global Fund and facilitated through Yabhysa, which provides accommodations for patients and their families traveling to

Soebandi Hospital. Collaborative partnerships further strengthen Sekawan's TB, involving institutions like POP TB, the Global Fund, the Health and Social Services Departments, local health centers, hospitals, the Bakrie Foundation, and academic institutions such as the University of Jember's Public Health Faculty. The community also works closely with other organizations, including HIV support groups, Yabhysa, Rekat Peduli Indonesia, Pejuang TB-MDR Gresik (Petir), and Persakmi. Program assistance from POP TB continues to bolster the community's efforts, enhancing its ability to deliver impactful support to TB-RO patients in Jember.

#### *2.1.4 Challenges in Sekawan's TB Community*

Sekawan's TB encounters several significant challenges in its operations, primarily related to limited human resources and insufficient funding. The lack of personnel impedes the smooth execution of administrative tasks, such as drafting budget proposals and organizing events. A small member base also constrains the community's ability to effectively handle emerging TB-RO cases. The absence of a fixed salary for members has led to decreased commitment, as some have left the organization for more stable opportunities. Additionally, low educational levels among certain members pose further difficulties in achieving the community's objectives, as noted by Informant AZ.

Funding constraints exacerbate these challenges. Financial contributions from POP TB are restricted to specific patient-focused activities, such as FGDs, while initial funding from KNCV ceased after three years. Donations primarily target direct patient needs, including nutrition and medical supplies, leaving minimal resources for mentors or broader community operations.

Sekawan's TB also grapples with internal conflicts among members and challenges related to patient compliance. Many patients struggle with the severe side effects of TB-RO medications and the lengthy treatment duration, leading to reduced motivation to complete therapy. Denial of diagnosis by some patients further complicates the community's efforts, delaying the provision of necessary support and interventions. These obstacles collectively hinder the organization's ability to fulfill its mission effectively

#### *2.1.5 Sekawan's TB's Efforts to Overcome Challenges*

Sekawan's TB implements a multifaceted approach to address its challenges, particularly in human resources, funding, and patient compliance. The organization endeavors to expand its membership by actively recruiting both survivors and non-survivors, with a preference for individuals possessing higher educational qualifications to enhance administrative capabilities. Informant AZ plays a pivotal role in fostering member skill development by providing training in community management, reporting, budgeting, and administration. This strategy not only bolsters member contributions but also empowers them to more effectively manage

organizational demands.

To address financial constraints, Sekawan's TB optimizes the use of existing funds, ensuring their efficient allocation towards essential activities such as FGDs and training sessions. Any surplus funds are prudently directed to the community's cash reserves. Moreover, the community seeks additional financial support by partnering with the Jember Health Office to secure allocations from the regional budget (APBD), successfully obtaining funding for two consecutive years. Additionally, fundraising events, such as concerts held in cafes and restaurants, are organized to generate supplementary donations for patient support.

Sekawan's TB actively addresses internal conflicts among members through regular discussions and evaluations, promoting a harmonious working environment. To tackle patient non-compliance, the community collaborates with the Health Office and local healthcare centers (puskesmas) to engage families, neighborhood leaders, and neighbors in the patient care process. These stakeholders are enlisted to provide support through negotiation, motivation, and education about TB and its treatment.

In addressing cultural barriers associated with traditional healing practices, the community adopts a balanced approach by educating patients and their families on the importance of medical treatment while respecting their choice to pursue alternative remedies. This strategy ensures continued patient engagement in their medical regimens, thereby reducing the likelihood of treatment discontinuation.

#### *2.1.6 Forms of Activities of Sekawan's TB Community*

Sekawan's TB Community engages in a diverse range of activities, encompassing patient support, training, internal meetings, reporting, the TB Army initiative, advocacy, counseling, fundraising, and the distribution of nutritional packages and medical equipment, as well as Focus Group Discussions (FGDs). The community provides substantial support to patients facing economic challenges by initiatives such as purchasing livestock, like chickens, for patients to manage. Sekawan's TB organizes its patient support activities based on the specific roles of its members, incorporating Communication, Information, and Education (CIE) regarding treatment, transmission, prevention, and management of drug-resistant tuberculosis (DR-TB). Supporters are officially sanctioned by the Health Office through an authorization letter.

Patient support emphasizes granting autonomy and informed choices to patients and their families, avoiding coercion in treatment adherence. Supporters are trained to offer optimal solutions to patients' complaints. They must maintain good health and utilize comprehensive personal protective equipment (PPE), including N95 masks and hand sanitizers, to mitigate the risk of transmission. Additionally, they must consider environmental factors; for instance, if a patient's home lacks adequate air circulation, supporters conduct their assistance outdoors to prevent DR-TB transmission. Beyond direct patient support, Sekawan's TB engages in socialization and counseling to enhance public awareness. The TB Army, a structured activity

within Sekawan's TB, is managed by a dedicated coordinator. Sekawan's TB frequently collaborates with the Health Office, Yabhysa, and the Ministry of Health to conduct training sessions, attended by select members based on a predefined quota. The community also facilitates training for patients to help them overcome economic difficulties.

Furthermore, Sekawan's TB conducts FGDs with patients every three months, addressing themes set by POP TB and funded by the organization. These discussions aim to address treatment barriers, side effects, stigma, and discrimination. FGDs are typically held at the Lung Hospital, utilizing the hospital's facilities and involving healthcare professionals who provide motivational support and education on DR-TB. Following each FGD, Sekawan's TB is required to prepare a comprehensive activity report and submit it to POP TB and associated institutions as evidence of the event's execution. Additionally, Sekawan's TB holds internal meetings quarterly for evaluations and social gatherings, hosted at members' residences on a rotating basis.

#### *2.1.7 Existence of Sekawan's TB Community*

Initially, Sekawan's TB community was primarily recognized by patients, their families, and the health sector. However, following the recruitment of non-survivor human resources and the commencement of an internship program in 2022, the community has garnered broader recognition through social media platforms and governmental collaborations. Sekawan's TB has expanded its partnerships with institutions beyond the health sector, including the Social Affairs Office and the YDSF. Moreover, it has established itself as a practical training and internship venue for students pursuing social and health sciences.

## **2.2 Stages of Organizing a Tuberculosis Survivor-Based Community in Jember Regency**

The Sekawan's TB community was established to support the government in accelerating the elimination of drug-resistant tuberculosis (DR-TB) in Jember. Predominantly comprised of DR-TB survivors who volunteer their time, this non-profit organization continuously seeks donors to fund its initiatives, particularly those aimed at supporting DR-TB patients. Sekawan's TB operates under the external oversight of entities such as POP TB, Yabhysa, and the Jember Health Office, with activity reports serving as a form of accountability. The stages of organizing the Sekawan's TB community largely align with the concepts presented by Mukhotib MD in Adini (2013), though not all steps are fully implemented. The organizational stages include:

#### *2.2.1 Stage of Idea Presentation*

The concept of Sekawan's TB in Jember Regency originated from a recovered DR-TB survivor who had previously been active in a DR-TB survivor organization in Malang. The lack of attention to DR-TB cases in Jember, which necessitated patients seeking treatment in other

cities, motivated this survivor to support DR-TB patients in Jember. Driven by empathy and concern for patients still undergoing treatment, the individual returned to Jember to provide independent support, receiving a positive response from the Deputy TB Supervisor of the Jember Health Office.

This initiative aligns with the characteristics of a Community-Based Organization (CBO), which often stems from a survivor's desire to address the challenges faced by DR-TB patients (Hoe, 2015). The survivor's initiative was supported by the government and several NGOs, all sharing the common goal of establishing a survivor-based TB community in Jember. The community acts as a governmental partner in supporting programs aimed at accelerating TB elimination in the region. This finding underscores the critical role of CBOs in resolving local issues by assisting patients and improving their welfare and social functionality (Hoe, 2015).

### *2.2.2 Stage of Building Stakeholder Networks*

The TB Supervisor at the Jember Health Office facilitated the creation of a collaborative network to realize the vision of the DR-TB survivor by coordinating with various stakeholders, including hospitals, volunteers, and NGOs. This collaboration involved health promoters from Jember Pulmonary Hospital, the hospital director, the Petir Community, and the KNCV Foundation, all of whom supported the establishment of a DR-TB survivor-based community in Jember.

Building partnerships with stakeholders to oversee the community also entailed recruiting other recovered DR-TB survivors willing to act as agents of change in eliminating DR-TB in Jember (Hoe, 2015). Fifteen DR-TB survivors were invited to join these efforts. These survivors were selected based on their shared experiences as DR-TB patients, reflecting the characteristics of social communities (Wenger, 2002). Their common intentions, beliefs, and preferences as individuals who had endured DR-TB united them to work toward a shared goal: supporting DR-TB patients and contributing to the elimination of DR-TB in Jember (Scermerhorn in Izzati et al., 2023)

### *2.2.3 Stages of Human Resource Training*

The Sekawan's TB Community, established by DR-TB survivors, requires comprehensive preparation, including material consolidation training. This training aims to create a community dedicated to managing DR-TB patients in Jember Regency and to enhance the capacity of human resources within the community. It also seeks to prepare members with lower educational backgrounds to ensure sustainable growth of the community even without ongoing supervision from external parties. Furthermore, the training and material consolidation serve to build relationships and foster a sense of ownership among community members (Tattersall in Ujjanto, 2019). This training received financial support from the KNCV Foundation and the Global Fund, which subsequently became key NGO partners supporting Sekawan's TB Community (Bennet in Saleh, 2022). The training activities were conducted to fortify the

foundation of DR-TB survivors through capacity building (Schutz and Sandy in Ujjianto, 2019).

The training sessions were held in 2016 at Aston Jember Hotel over three separate occasions within two consecutive weeks. DR-TB survivors received training from several partners, including KNCV, Rekat Community, Jember Health Office, Aisyiyah Foundation, and the Ministry of Health. These sessions aimed to improve the quality of human resources or community members by providing guidance on leadership, management, and organizational skills to strengthen the community's capacity to serve as companions for DR-TB patients (Schutz and Sandy in Ujjianto, 2019). Following multiple training and socialization sessions, the community was formally established and recognized by relevant authorities. The primary goal of this community is to assist the government in reaching and addressing the challenges faced by DR-TB patients in Jember.

#### *2.2.4 Stages of Community Formation*

During this stage, the election of the board, determination of the community's name, and registration of its legal status were undertaken. The board of Sekawan's TB was elected through a voting process at the conclusion of the training. Informant AZ, the initiator of the community, was appointed as the chairperson, and informant FM, another survivor, was appointed as the vice-chairperson. Both have actively contributed to the community's activities since its inception, given their significant contributions as volunteers aiding the community's growth. The next task involved determining the name, meaning, logo, and philosophy of the community. The community's name and identity resulted from contributions by the TB Supervisor of the Jember Health Office and Promkes RS, the community's working partners (Saleh, 2022).

The name Sekawan's TB, derived from Javanese with a 4S logo, symbolizes the values of being grateful, spirited, patient, and successful. This name has become the community's identity, enabling Sekawan's TB to enhance its presence as the first DR-TB survivor community formed in Jember, with the aim of assisting and addressing the problems faced by DR-TB patients. Subsequently, the chairperson took the initiative to secure the community's legal status by creating a notarial deed and registering it with the Ministry of Law and Human Rights of the Republic of Indonesia. Additionally, the chairperson formulated the community's Articles of Association and Bylaws, which serve to regulate the community's vision, mission, duties, and goals, providing guidelines for executing its programs and activities.

#### *2.2.5 Stages of Planning Community Activities*

At this stage, Sekawan's TB Community began to outline the activities to be conducted, which include patient support as the primary activity, involving accompanying and supervising DR-TB patients during their treatment at relevant health centers or hospitals to ensure they receive appropriate treatment and medication. Training for patients aims to increase the capacity of those who have lost their jobs due to severe drug side effects, leveraging available

resources. Training community members is intended to enhance their skills and responsibilities, ensuring the continuation of planned activities (Schutz and Sandy in Ujianto, 2019). Internal meetings and reporting are held quarterly for evaluation purposes, to identify areas needing improvement and assess the success of services provided (Tattersall in Ujianto, 2019). Peer education targets peer TB patients or adolescents by providing educational activities.

Communication, Information, and Education (CIE) is provided to patients, their families, and other communities to increase public participation and awareness about DR-TB, thereby reducing discrimination against patients and their families (Hoe, 2015). The TB Army program aims to increase case detection rates and ensure compliance of DR-TB patients who have unilaterally discontinued their treatment. Focus Group Discussions (FGDs) are conducted to enhance participation and address patient complaints, with themes provided by supporting institutions like POP TB. Socialization and counseling activities are offered not only to patients but also to their families and surrounding communities as a preventive measure against DR-TB transmission, particularly among vulnerable groups as identified by the Ministry of Health (2022). Finally, donation collection and the distribution of nutritional packages provide economic assistance to patients, supported by network cooperation efforts as a funding factor (Hoe, 2015).

#### *2.2.6 Stages of Community Activity Implementation*

DR-TB patients accompanied by Sekawan's TB have varying conditions due to drug side effects, influenced by their immunity and lifestyle. These side effects range from mild to severe, affecting patients' social functioning, work, and mental health. Sekawan's TB addresses these issues based on patients' needs. The community conducts support activities for DR-TB patients in Jember Regency and socialization for the broader community. The goals are to increase knowledge about DR-TB, reduce discrimination against patients, and combat myths related to the disease. The community specifically targets handling DR-TB patients based on the members' experiences as DR-TB survivors (Prasad, 2023). The implementation of patient support strives to provide equal assistance to all patients regardless of social status (Prasad, 2023). Therefore, Sekawan's TB continuously works to secure resources through cooperation and networks. It aims to help DR-TB patients meet needs across various aspects, such as economic, health, psychological, and social (Hoe, 2015). Findings show that Sekawan's TB genuinely does not differentiate among the target groups it supports, allowing all DR-TB patients to receive equal services without consideration of social status.

As a result of this support, Sekawan's TB is trusted to oversee more than 40 health centers and sub-centers in the Jember area. Currently, there are 100 DR-TB patients accompanied by Sekawan's TB Community. The number of patients fluctuates depending on DR-TB case detection and recovery rates. These factors determine the success of the services provided by the community, serving as benchmarks for evaluations and gaining trust from the

public and donors, thereby continuing to increase participation (Datta in Hoe, 2015). Patient data is obtained from hospitals, health centers, Yabhysa, and the Jember Health Office. Sekawan's TB coordinates with Yabhysa and the Jember Health Office to divide support tasks, which are then distributed by the chair of Sekawan's TB. Besides collaborating with health institutions, the community also partners with various other institutions, such as educational and social organizations, as well as individuals or private entities, which become supporting factors for overcoming challenges like funding, human resources, and technical issues (Hoe, 2015).

Sekawan's TB is a non-profit community that does not seek profit, and thus often faces practical difficulties and obstacles related to funding. Funding sources and human resources have become the two main issues discussed in this research's findings (Kwok in Saleh, 2022). Sekawan's TB aims to ensure the sustainability of service programs for patients by leveraging member contributions and organizing events to seek donors, such as live music performances at restaurants and cafes (Hoe, 2015). Over time, this has caused difficulties in the human resources aspect (Kwok in Saleh, 2022), which is necessary for managing community activities and programs, especially administrative activities. Additionally, the low educational levels of community members impact the human resources issue. This has led Sekawan's TB to initiate recruitment to increase the community's human resources, becoming agents of change participating in Sekawan's TB membership (Hoe, 2015).

### *2.2.7 Monitoring Stages*

At this stage, the organization of Sekawan's TB is monitored by external parties such as the Jember Health Office, Lung Hospital, and POP TB. Monitoring is conducted by submitting activity reports, which are then discussed in evaluations with supervisors from Yabhysa. These parties assist Sekawan's TB and contribute to community improvements, ensuring the community's journey is supported by related entities (Bennet in Saleh, 2022). During this stage, Sekawan's TB must prepare reports to be submitted to POP TB via mail as proof that the activities have been successfully carried out. POP TB provides technical and financial assistance (Bennet in Saleh, 2022) to Sekawan's TB community regularly, making these reports necessary proof of successful activities. The reports are also submitted to several institutions collaborating with the community.

### *2.2.8 Stages of Activity Evaluation*

Sekawan's TB conducts two types of routine evaluations. The first type is internal evaluation, called 'anjangsana,' held every three months to reflect on activities and strengthen member camaraderie. These internal evaluations are held at rotating members' homes. The second type is external evaluation, conducted by sending activity reports to Yabhysa for evaluation. These reports include detailed assessments of DR-TB patient conditions and complaints by supervisors. These evaluation activities serve as benchmarks for the community

to continue developing and enhancing its ability to support DR-TB patients (Tattersall in Ujjianto, 2019)

### 3. Conclusion

The Sekawan's TB Community in Jember is a Community-Based Organization (CBO) operating under the supervision of NGOs and the government, and is funded through contributions from affiliated entities. While it exhibits numerous CBO characteristics, this community is not entirely grassroots as its structure follows the framework of supporting institutions. Sekawan's TB faces two primary challenges: a shortage of human resources and funding.

As a survivor-based CBO, Sekawan's TB community progresses through eight organizational stages that do not fully align with those outlined by Mukhotib MD. These stages include: first, the stage of presenting the initiator's ideas through independent support, which received positive reception from the Deputy TB Supervisor of the Jember Health Office. Second, the stage of establishing stakeholder networks, encompassing hospitals, government agencies, NGOs, other DR-TB survivors, and various communities, to facilitate the formation of the first survivor-based DR-TB community in Jember. Third, the human resource training stage aimed at reinforcing the basics of community management, leadership, and organization to enhance the quality and capacity of DR-TB survivors in supporting patients in Jember. Fourth, the community formation stage involving the election of management through voting, and the development of a name, philosophy, meaning, and logo to serve as the community's identity. Fifth, the stage of planning community activities, such as patient support, training for patients and community members, internal meetings and reporting, peer education, fundraising, counseling, and focus group discussions (FGDs). Sixth, the stage of implementing community activities in accordance with the previously designed plans and programs. Seventh, the monitoring stage, which serves as a supervisory mechanism from NGOs and related entities overseeing Sekawan's TB operations. Finally, the eighth stage involves the evaluation of activities, reflecting on the planned initiatives and programs.

The outcomes of these eight organizational stages have significantly enhanced the quality and capacity of resources within the community, thereby expanding its presence and earning the trust of the public and stakeholders. Additionally, Sekawan's TB community organization has yielded substantial benefits for the DR-TB patients it supports. These benefits include the reduction of stigma and discrimination, improvements in patient welfare and recovery rates, and the establishment of a source of education and support for patients and their families.

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