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Article

Training for Mental Health Volunteers of People Living with Schizophrenia in the COVID-19 Pandemic in Bangkalan City

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Abstracts

Introductions: The global coronavirus-19 (COVID-19) pandemic disproportionately burdens people with schizophrenia and related disorders. Access to mental health providers in rural areas was still far from expected. People with schizophrenia in low and middle-income countries, including Bangkalan City, often lack access to evidence-based treatments. We hypothesized that psychoeducation might improve Mental Health Volunteers' (MHV) knowledge and skills to help people with schizophrenia in rural areas. Furthermore, we want to identify the obstacles and practical solutions essential to improving the community's mental health in Bangkalan City. **Methods:** The total participants were 134 MHV from the Department of Health, Bangkalan City. The data was collected in pretest and posttest on each workshop session and Focus Group Discussion (FGD). **Results:** There were significant improvements in the knowledge and skills about Schizophrenia of MHVs and programmers from the Department of Health, Bangkalan City ($p<0.01$). The three most common problems raised in FGD were communication with people with schizophrenia and their families due to health protocols, appeals from community leaders contrary to health policies, and family conflicts. **Conclusions:** Training for MHV in the Department of Health, Bangkalan City, has improved their understanding of schizophrenia and its interventions, their communication skills with people with schizophrenia and their families, and their skills to handle psychiatric emergencies related to schizophrenia. The three most common problems and the solutions were agreed upon during FGD.

Keywords: Covid-19, Schizophrenia, Mental Health Volunteer (MHV), Bangkalan City.

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Introductions

The global coronavirus-19 (COVID-19) pandemic has had an unprecedented impact on populations worldwide and is expected to place a disproportionate burden on people with schizophrenia and related disorders. Previous outbreaks had persistent mental health effects following the 2003 Severe Acute Respiratory Syndrome (SARS) pandemic, showing significantly increased psychiatric disorders and psychological distress rates. Data collected from SARS survivors stated that half of the survivors experience various kinds of psychiatric disorders in the medium and long term, even after one year of infection. Moreover, more than half of survivors were at increased risk of experiencing psychiatric disorders [1].

Schizophrenia is the 7th most common cause of the Global Burden of Disease 2000 reported in 2001 [2], and is one of 10 diseases that cause disability-adjusted life years [3]. Studies found that people with schizophrenia are more susceptible to contracting COVID-19 infection and its complications due to their cognitive deficits, comorbidities, disparities in health care, discrimination, and stigmatization [4]. Lack of cognitive capacity, insight, and effective coping led them to difficulties in the protective measures to prevent infection, such as wearing proper masks and physical distancing. Comorbidities derive from physical illnesses and drugs' adverse effects, such as metabolic problems and hypersalivation, which makes them more prone to aspiration, smoking habits, and substance use. Despite many difficulties, people with schizophrenia often have their symptoms underdiagnosed, are less likely to be intervened, and receive poorer care than the general population [5–7], [8]. Clinicians and social workers must educate them about COVID-19 precautions and measures according to their understanding capacity. Continuity of attention and care needs to be maintained long-term [9].

After being hospitalized for a relatively short period, most people with schizophrenia are sent back to their respective homes, which means they return to their families. On the other hand, this change became immeasurable because healthcare facilities could not replace natural social integration in the family. Meanwhile, living with people with schizophrenia will burden and restrict all family members [10],[11].

Studies showed that access to mental health providers in rural areas was still far from expected. Limited knowledge and highly expressed emotions were still a concern [12]. Family and caregivers played an essential role in supporting the patients. Unfortunately, families, especially the ones who took the caregiving role, often felt substantial pressure. Hence, they also needed urgent attention [13].

Evidence-based care for schizophrenia mentions assertive community treatment and intensive care management, highlighting personal contact with patients and families in homes and community settings [5]. Typically, people with schizophrenia have smaller and poorer-quality social networks [6], [7]. The provision of social support, social adaptation, and drug treatment play a principal role in schizophrenia treatment. It is distinct that doctors and nurses in local public health centers, as well as mental health volunteers with whom patients develop significant relationships, have an irreplaceable place in the mental health field. Community support, even only casual contacts at markets or cafes, has been correlated to higher and better recovery and community integration for people with schizophrenia [6], [14], [15].

Most people with schizophrenia who live in low and middle-income countries often lack access to evidence-based treatments. World Bank's Disease Control Priorities suggests that family support, community-based rehabilitation, and support groups should be prioritized in these settings and delivered by non-specialist workers, including lay health workers and mental health volunteers. These interventions may address critical challenges of the needs of patients in low and mid-

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dle-income countries [16], [17].
Schizophrenia has not been widely known to people living in the peripheral areas, including the Mental Health Volunteers (MHV) in Bangkalan City. Thus, we hypothesized that psychoeducation about schizophrenia could improve their knowledge and skills to be applied in their daily practice. We also aim to identify the obstacles in their lap and, more importantly, the practical solutions to improve the community's mental health in Bangkalan City.

Methods

The total participants were 134 MHV from the Department of Health, Bangkalan City. They registered in advance for the training. The research design used – a post-test design. Face validity of all sets of pretest and posttest were higher than 85%. The time of training was carried out in August 2022 in 2 consecutive days. The training was divided into four workshops and 1 Focus Group Discussion (FGD) session. The training material consisted of Understanding schizophrenia (session 1), The interventions (session 2), Schizophrenia problems during the COVID-19 pandemic (FGD Session 3), Communicating with people with schizophrenia and their families (session 4), and Psychiatric emergencies related to schizophrenia (session 5). Each session was conducted within a 90-minute predetermined time. The training was conducted on-site in Bangkalan City. Participants who did not participate in all four sessions and completed the four sets of pretests and posttests were excluded.

Results

Results from Workshop Sessions 1, 2, 4, and 5

The participants' response rate was 52.9%, or 71 participants who met the inclusion criteria. Female (54 people, 76.05%) participants were about three times more than male (17 people, 23.95%).
A total of 47.1% or 63 participants did not meet the inclusion criteria because they did not attend all training sessions or did not do all pretests and posttests for several reasons, including being late due to the training location that was 50 kilometers away from their place, or they left the training for other activities.
The MHVs' knowledge changes could be assessed from the mean pretest and posttest scores, shown in Table 1. From sessions 1, 2, 4, and 5, there were significant changes in the MHVs' understanding regarding Schizophrenia, schizophrenia intervention, communicating with people with Schizophrenia and their families, and psychiatric emergencies related to Schizophrenia with significance values of $p<0.01$. There were significant improvements in the knowledge and skills about Schizophrenia of MHVs and programmers from the Department of Health, Bangkalan City.

Table 1. Mean Pretest and Posttest Scores

	Mean pretest score	Mean posttest score	Comparation analysis
Session 1 Understanding schizophrenia	66,47±23,6	79,57±19.08	0,0000*
Session 2 Schizophrenia interventions	35,49±17,71	69,15±22,02	0,0000*
Session 4 Communicating with people with schizophrenia and families	53,66±12,56	58,67±12,93	0,007*
Session 5 Psychiatric emergency related to schizophrenia	78,30±15,85	86,33±11,61	0,0000*

*significance based on $p<0.01$ using the Wilcoxon Signed Rank Test comparison

Results from Session 3 (Focused Group Discussion regarding mental health services during the COVID pandemic)

The most obstacles found in Bangkalan City were raised during the third mental health services training session during the COVID-19 pandemic and were conducted by an FGD. MHVs and programmers presented nine problems they found in their practice field, including:
1. Communication with people with schizophrenia and their families (due to health protocols)
2. Coordination with the mental health team
3. Health protocols/vaccine compliance (mandatory topic)
4. Family conflicts
5. Local (cultural) beliefs that hinder proper management of schizophrenia
6. Availability of drugs and other resources
7. Coordination with other agencies and stakeholders
8. Appeals from community leaders who are contrary to health policies
9. Referral flow during the pandemic

Those nine problems were found by conducting a poll when participants registered for the training. The three most common problems in the field were communication with people with schizophrenia and their families due to health protocols, appeals from community leaders contrary to health policies, and family conflicts. The results of the discussions raised in the forum are set out in **Table 2**.

Table 2. Problems related to mental health services in the community during the COVID-19 pandemic and alternative solutions that emerged from the results of the FGD

Problems		Alternative solutions raised from FGD
Communication with people with schizophrenia and their families (due to health protocols)	1.	Keep visiting people with schizophrenia's houses with strict procedures
	2.	Keep communicating via WhatsApp application, making a WhatsApp group between MHV and families of people with schizophrenia
	3.	Keep communicating via short messages service (SMS)
	4.	Medication and consultation with a medical professional
	5.	Coordination between all teams, health workers, and MHVs to reach the common goal of helping people with schizophrenia and encouraging their families
	6.	Collaboration between MHV and families, holding meetings
	7.	Approaching community leaders, involving religious leaders as respected figures, involving health workers. Set a common goal and be patient because it would take a long process. Zoom meeting was preferably during the pandemic, or face-to-face meeting when the pandemic is over. Conduct meetings once a month according to the needs.
	8.	Approaching the closest people who were respected, such as religious leaders and village officials
	9.	Socialization of the Covid-19 vaccine

Appeals from community leaders who are contrary to health policies	1.	Breaking the stigma by conducting outreach to community leaders and the surrounding community (sharing the difficulties faced after being released from the shackles and about the limited stock of drugs)
	2.	Conducting outreach to people with schizophrenia families about the importance of health protocols
	3.	Collaboration with all parties (family – relatives – health workers – authorities)
	4.	Role modeling of COVID-19 protocols compliance by MHV
	5.	Socialization of health programs and policies to the community, including inviting community leaders
	6.	Creating TPKJM (Tim Pelaksana Kesehatan Jiwa Masyarakat / community mental health team) in each sub-district to accommodate community complaints related to mental disorders with cross-sectoral collaboration (sub-district – public health facilities – MHVs) to resolve health problems. It would be easier to handle costs and budgets with TPKJM
Family conflicts	1.	Disseminating the correct information, understanding, and prevention so that conflicts do not recur
	2.	Conducting person by personal approach continuously, accompanied by religious leaders, community leaders, and the survivors
	3.	Family psychoeducation about expressed emotions
	4.	Involving the primary care and the Department of Health to provide referrals. The health workers should be alert to face people with schizophrenia who are sometimes emotional. A special team with several physically strong people should be formed to handle the people with schizophrenia if needed

Discussions

Psychoeducation to family and caregivers needs to be done by mental health specialists and non-specialists, including MHV, who are skilled in expressing emotions and the meaning of psychopathological signs in an understandable way. Their knowledge about schizophrenia will lead them to understand the patient's drama and behavior. Education also includes effective communication, problem-solving, and coping skills to find the family's internal strength despite stigmatization and to help them develop social support and social integration [18].

In addition to human needs, Alderfer's theory, condensed from Maslow's theory of basic needs, applies to people with schizophrenia. As the main conditions during a pandemic, the existence needs consist of health and security. The relatedness needs to include interpersonal needs, family needs, and humanistic concerns as the most important ones. The growth needs can be seen as information and knowledge needs [1]. Humanistic concern highlights the necessity of psychosocial support as a part of health services for patients with schizophrenia [5].

The COVID-19 pandemic also negatively affected the mental health of the family and caregivers of people with schizophrenia. In

contrast to the pre-pandemic era, they experienced more unpredictable and unusually long-time anxiogenic stimuli. Uncontrollable distress related to illness and social isolation may exacerbate a higher incidence of anxiety, depression, paranoia, new psychotic episodes, less psychological well-being, worsening of psychopathologies, and even suicidal thoughts [4], [19]. Research has proven that 83% of relatives and family of someone who suffers from schizophrenia experience financial, emotional, and practical burdens [14].

The pandemic also put people with schizophrenia and their caregivers in more difficulty accessing outpatient clinics and psychotropic medications. They may have more financial hardship, increased impoverishment, and less psychosocial support, which is a crucial aid to cope with stress and help them in treatment [4]. Environmental stressors, notably social isolation and excess exposure to pandemic news, may worsen former stress sensitivity and escalate stress-related cortisol levels and dopamine release. To the prone individuals, it may also trigger psychotic symptoms and suicide. Antipsychotics may not be sufficient to prevent relapse. Due to negative stigma, psychiatric patients must also be assisted in accessing medical providers to receive appropriate examination and treatment [5].

Barriers to accessing medical providers may lead patients to medication nonadherence. There is a higher risk of relapse, given the emotional suffering of those diagnosed with schizophrenia, because they are already vulnerable to pandemic attacks, their limited access to the community, and the risk of discontinuation of treatment. The whole family, both relatives, and people with schizophrenia, may be concerned about the current situation and find it easy to relapse given the limited accessibility to mental hospitals because there are a large number of infections in the hospital. Family members caring for a person diagnosed with schizophrenia perceive guilt for not recognizing the early symptoms. They may feel it even more intensely during this pandemic when mental hospitals operate differently and only make hospitalizations in emergencies. Proper care is crucial to prevent further decompensation and deterioration of the patient and avoid more strains on the health care system [5], [18].

Pandemic stressors indeed impact psychosocial aspects in the form of fear related to the loss of loved ones, health problems, loss of employment, and deteriorating well-being related to COVID-19 stigma and social isolation [5]. Social distancing measures can be an additional factor in increasing family conflict situations due to the added mental stress and the fact that they must stay together most of the time. Since the pre-pandemic period, social isolation and lack of community support are other fundamental problems which may now be felt even more strongly [20]. The result of pandemic-related distress is a resultant between the stressor severity and individual factors, such as age, ego defense, coping mechanism, distress tolerance, and previous psychopathologies [21].

The research found that the family and caregivers' burden was significantly correlated with care difficulties during isolation and lockdown. Several main concerns of family and caregivers are fear of catching COVID-19, the potential relapse of the patients, and economic concerns that hold them back from taking patients to medical providers [1], [19].

The family burden of patients with schizophrenia is associated with the peculiar symptoms and unpredictable behavior of schizophrenia. Family burdens can be categorized as subjective and objective burdens. The emotional burden is anxiety, pain, despair, insecurity about the sick person, strange behavior, aggressivity, and limited capacity for self-control and autonomy. Parents of people with schizophrenia or those who are concerned often express their concerns about the future and the individual's life trajectory after death. The objective burden

includes conflicts and neglect from other family members and deterioration of social relationships as they feel ashamed of the sick person. Lack of social support got much worse in the pandemic era [18], [22].

Being part of a family with schizophrenia also means facing obstacles in doing relaxation activities. This difficulty can lead to fatigue during this period. Loss of work or a decrease in income and financial problems caused by medical expenses are pre-pandemic problems exacerbated by the pandemic [23]. Besides, symptoms of schizophrenia, including negative symptoms, aggression, and other behaviors, are often not understood by the family and caregivers of the sick person. They attribute the symptoms to the ill person, not the sickness, and perceive them according to their perspectives. Sometimes, they feel that the ill person intends to provoke them, then accuse the sick person of bad will. They often choose to hide the burden and exhaustion of caregiving [18].

Psychosocial interventions typically align with personal recovery principles, such as attaining a fulfilling and valued life. The Schizophrenia Patient Outcomes Research Team (PORT) recommends eight psychosocial interventions: assertive community treatment, supported employment, cognitive behavioral therapy, family-based services, token economy, skills training, and psychosocial interventions for alcohol, substance use disorders, and weight management, which further impact patients' functioning, relapse, and hospitalization. The most substantial evidence was assertive community treatment, family-based intervention, and psychoeducation [16], [17].

Evidence from low and middle-income countries supports the feasibility and effectiveness of community-based psychosocial interventions for schizophrenia as a primary adjuvant treatment to facility-based care [16]. A better perspective and understanding of mental health significantly impact the patient's social and professional rehabilitation success. Successful recovery of people diagnosed with mental health problems will inspire many others worldwide. So, the pandemic can also be an opportunity to improve social care services to build multidisciplinary intervention systems and networks [18].

Conclusions

The COVID-19 pandemic increased the burden of people with schizophrenia and families living with them. Comprehensive psychoeducation and training are needed to alleviate their suffering. Activity conducted for MHVs in the Department of Health, Bangkalan City, has increased their understanding of schizophrenia and its interventions, their communication skills with people with schizophrenia and their families, and their skills to handle psychiatric emergencies related to schizophrenia. FGD is an effective way to find and target the problems the MHVs find in their daily practice field. The three most common problems in Bangkalan City were communication with people with schizophrenia and their families due to health protocols, appeals from community leaders contrary to health policies, and family conflicts. Some alternative solutions were agreed upon for those problems and are ready to be implemented.

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Conflict of interests

The authors have no conflicts of interest to declare.

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