

## **EXPLORING THE LIVED EXPERIENCES IN FORMAL VOLUNTEERING AMONG PEOPLE WITH MENTAL ILLNESSES (PWMI) IN SELANGOR**

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### **ABSTRACT**

Volunteering has been linked to various psychological benefits. However, studies on volunteerism among people with mental illnesses (PWMI) are scarce. The objective of this study is to explore the lived experience in volunteering activities among people with mental illnesses in Selangor. Qualitative phenomenological research design was used and data were collected using semi-structured interviews. Ten informants aged between 20-42 years old who participate in formal volunteering and diagnosed with various mental illnesses were recruited through purposive sampling method. Interview transcripts were analyzed using thematic analysis and revealed that volunteering is a mixed experience for PWMI where they have gained benefits and also face challenges and barriers. Volunteering serves as a therapeutic and productive activity that gives them a sense of self-satisfaction. However, their volunteering experience may also be disrupted by challenges that are contributed by their mental illness, such as burnouts, relapses, and triggers. Furthermore, lack of family support and stigma may pose barriers for PWMI from volunteering. This study reveals the benefits as well as obstacles in volunteering for PWMI. The findings could be used to guide policymakers, mental health professionals, and non-profit organizations in designing supported volunteering programs as an effort to promote social inclusion for this population. Finally, future studies should consider investigating the prevalence of PWMI in formal volunteering.

### **Keywords:**

*Volunteerism, mental health problems, volunteer motivation, volunteering challenges, phenomenological study*

### **INTRODUCTION**

Volunteering is one of the many prosocial activities which has gained wide interest from scientists of various disciplines, such as psychology, public health, and mental health. According to Omoto et al. (2020), volunteering is a type of prosocial activity where individuals actively and willingly search for opportunities to provide help to other people in need. Volunteers give their time, energy, skills, and resources to benefit the needy without expecting monetary or non-monetary rewards in return.

The benefits of volunteering on the general population has been well established by the robust body of scientific literature. Improved mental health, reduced depression, improved life satisfaction, and having a sense of self-worth are among the many psychological benefits that have been identified (Lawton et al., 2021; Tabassum et al., 2016). However, despite the strong evidence on the general population, there is insufficient data on the benefits of volunteering among specific vulnerable groups which could possibly gain benefits from it, such as people living with mental illnesses (Held & Lee, 2020).

Before discussing further on mental illness, it is crucial to address the issue of terminology in referring to this vulnerable population. Debates arise as to which terminology is best used due to the stigma and discrimination associated with certain terminologies, such as “mentally ill people”, “schizophrenic”, and “autistic person” (Granello & Gibbs, 2016; Jensen et al., 2013). Thus, Granello and Gibbs recommended the use of person-first language which separates “...the identity of the individual from any clinical diagnosis” (2016). For this population, the terminologies “person with mental illness” or “people with mental illnesses” are recommended as they are more appropriate and utilize person-first language. This paper will use the second terminology, “people with mental illnesses”, in its abbreviated form “PWMI” to refer to this population, as done by Pathare et al. (2014).

## **LITERATURE REVIEW**

In this section, an overview of the current literature on mental illness is presented, followed by an explanation of the concept of formal volunteering and its benefits based on the current body of evidence.

### ***Mental Illness***

Mental illness is a type of health condition that affects one's emotion, cognition, and behavior and may cause significant impairment in one's ability to function normally in his or her social, occupational, or family lives (American Psychiatric Association, 2013). In Malaysia, around 2.3% or almost half a million Malaysian adults were found to have depression, according to the latest National Health and Morbidity Survey (NHMS) 2019 published by the Institute for Public Health (IPH, 2020). This points to an urgent need to consider a more holistic intervention that may effectively promote recovery and wellbeing (Chieng, 2016).

Apart from medications and psychotherapies, social activities may also help PWMI to recover from their symptoms (Filia et al., 2019). Evidence from various studies suggests that any activities which promote social inclusion of PWMI in the community are reported to have a positive outcome on their wellbeing, which suggests the potential for volunteering as a psychosocial intervention (Held & Lee, 2020; Pérez-Corrales et al., 2019). However, several studies also reported some negative psychological-related outcomes among PWMI when volunteering, including stress, stigma, and discrimination (Farrell & Bryant, 2009; Read & Rickwood, 2009).

In Malaysia, there is paucity of data on the involvement in volunteering activities among PWMI. Local studies are more concerned about the changes in the Malaysian mental healthcare system, stigma, experiences of caregivers, experiences of mental health professionals, and complementary forms of therapy for mental illness (Ainul Nadhirah Hanafiah & Van Bortel, 2015; Naemah Abdul Rahim, 2016; Zul Azlin Razali & M. Faiz Tahir, 2016). Although studies on the social participation of PWMI exist, such studies are limited. For example, a study by Chieng (2016) in Johor Bahru focused on supported employment intervention among people living with schizophrenia only.

### ***Formal Volunteering***

According to Omoto et al. (2020), volunteering can be divided into several categories, including formal and informal volunteering. Formal volunteering occurs when an individual performs unpaid, voluntary work in a nonprofit group or volunteer program under the direction or supervision of a nonprofit organization. Examples of formal volunteering includes providing emotional support for PWMI as a peer volunteer, distributing humanitarian aids to Syrian refugees, providing care for the elderly in a nursing home, and fundraising for a local cause. On the other hand, informal volunteering is more spontaneous and is not coordinated by any formal non-profit organizations, such as unpaid babysitting, helping a neighbor with household chores, and donating one's clothes to a local charity.

With regards to the psychological benefits of volunteering, the bulk of evidence comes from studies on formal volunteering (Creaven et al., 2018; Lawton et al., 2021; Tabassum et al., 2016; Whillans et al., 2016). Numerous studies compared the psychological benefits of formal volunteering versus informal volunteering and found that the latter has no effect on preventing depression, whereby formal volunteering has a preventive benefit (Einolf et al., 2016). For example, a study conducted by Rosato et al. (2019) in Northern Ireland revealed poor mental health outcomes in the informal caregiving group, while those who are involved in formal volunteering report better psychological health. Therefore, based on the evidence, this study focused on formal volunteering and excluded informal volunteering.

## **METHODOLOGY**

This study used the phenomenological qualitative research approach to investigate the lived experiences of PWMI who are involved in formal volunteering activities. According to Creswell and Creswell (2018), phenomenology allows the researcher to understand how individuals give meaning to their worldview by looking at the phenomenon through the lens of the individuals' own experiences. This approach has been used in previous studies on volunteerism among PWMI (Pérez-Corrales et al., 2019; Read & Rickwood, 2009).

### ***Data Collection***

Semi-structured interviews were conducted through audio calls in October 2020. The interviews were conducted in the span of three weeks with three to four informants interviewed per week. Nine informants were interviewed using Skype application and one informant was interviewed over the phone. Each interview lasted for 35-75 minutes.

The interviews opened with questions about the activities and programs that the informants participate in the NGOs. Then, the questions evolved towards their lived experiences, including: "What do you like the most about volunteering?"; "How does volunteering relate with your illness?"; and "How has your illness changed since you started volunteering?" The informants were then asked to share some of the difficulties that they have experienced while volunteering. Finally, the interviews ended with the opportunity for the informants to share any other information pertaining to their lived experiences that might have not been mentioned previously.

### ***Informants and Sampling Strategies***

The study comprised of nine females and one male between the ages of 20-42 years old who have been diagnosed with mental illness and have been or are actively participating in volunteering activities in Selangor, Malaysia. Three individuals were recruited from a peer-led mental health non-governmental organization (NGO) in Petaling Jaya, Selangor, and seven were recruited from advertisements on online peer support groups. Approvals were obtained from the President of the NGO and a staff e-mailed the recruitment poster to all volunteers in their database. For the online support groups, the researchers obtained approvals from the respective groups' administrators who disseminated the recruitment poster to their members. Then, individuals who were interested to participate from the NGO and support groups contacted the researchers and were screened to discern their eligibility.

The inclusion criteria were individuals aged between 18 to 65 years old who have received a clinical diagnosis of any type of mental illness from a licensed mental health professional. They must be currently involved in volunteering work with any NGOs in Selangor, Malaysia and therefore, people who are only involved in informal volunteering were excluded. Additionally, they need to be in stable condition, not currently experiencing major symptoms of their illness, and are able to communicate. These criteria were implemented to ensure that the informants are able to communicate their experiences as best as possible. All informants who have been discerned as eligible were contacted to arrange for the interview and signed a consent form prior to the interview.

The sampling process continued until data saturation was reached, whereby no new information emerged from the data. This happened after seven informants were interviewed. However, the authors decided to continue sampling until 10 informants were interviewed, as recommended by Creswell and Creswell (2018) who suggested up to 10 informants for phenomenological studies. The majority of them are aged between 20-29 years old (8 informants), which represents the young- to mid-adult age group. Only one informant was aged between 30-39 and another one aged 40-49 years old, which represent the minority of the interviewed informants.

Furthermore, most informants are not married or single, while only three informants are married. In terms of employment status, four informants are employed, three are full-time students, two are unemployed, and one is a housewife. The majority of the informants are diagnosed with bipolar disorder (five informants) while three individuals with depression. Only one individual is diagnosed with social anxiety disorder (SAD) and one individual with attention deficit hyperactivity disorder (ADHD). Additionally, the majority of the informants are involved in several NGOs while one informant participates in only one NGO. Table 1 presents a summary of the informants' demographics and diagnosis.

Table 1: Demographics and Clinical Information of the Informants.

Total Number of Informants	10
Gender	<ul style="list-style-type: none"> <li>● Female (9)</li> <li>● Male (1)</li> </ul>
Age range	<ul style="list-style-type: none"> <li>● 20-29 (8)</li> <li>● 30-39 (1)</li> <li>● 40-49 (1)</li> </ul>
Marital status	<ul style="list-style-type: none"> <li>● Single or never married (7)</li> <li>● Married (3)</li> </ul>
Occupation	<ul style="list-style-type: none"> <li>● Employed (4)</li> <li>● Students (3)</li> <li>● Unemployed (2)</li> <li>● Housewife (1)</li> </ul>
Diagnosis	<ul style="list-style-type: none"> <li>● Bipolar disorder (5)</li> <li>● Depression (3)</li> <li>● Social anxiety disorder (SAD) (1)</li> <li>● Attention deficit hyperactivity disorder (ADHD) (1)</li> </ul>
NGOs Volunteered	<ul style="list-style-type: none"> <li>● Several (<i>e.g. mental health, humanitarian, Islamic NGO, etc.</i>) (9)</li> <li>● Islamic NGO only (1)</li> </ul>

### ***Brief Summary of Informants' Backgrounds***

In this sub-section, brief summaries of the informants' backgrounds are presented. Their real names have been replaced with pseudonyms to protect their identity.

Nur is a single, 24-year-old woman who lives with bipolar disorder. She has been involved in volunteering activities since studying overseas where she performed humanitarian work and continued doing so after returning to Malaysia. Now, she is currently doing an internship while volunteering with a mental health NGO in Selangor.

Unais is a 27-year-old married man who had been diagnosed with ADHD since primary school. His involvement in volunteering started while studying overseas where he held several portfolios in an NGO's student club. Now, he is currently pursuing his studies at a local university while serving as a general member of the same NGO.

Yasmin, a single, 29-year-old lady, had been diagnosed with bipolar disorder since high school. She co-founded a local peer support group a few years ago as a platform to share her

knowledge and experience on mental health recovery with others. Since then, she has also joined a mental health NGO and served as a volunteer doing mental health advocacy, peer support, and awareness. Now, she is currently working while also volunteering.

Kay is a 24-year-old single woman with Major Depressive Disorder. She had been diagnosed with mental illness three years ago by a psychiatrist. She started volunteering in university and continued to do so at a social enterprise after graduation. In 2020, she began volunteering as a researcher at a newly established mental health NGO. Now, Kay is pursuing her degree in Psychology at a local university.

Nurin is a married, 29-year-old lady who had been diagnosed with bipolar disorder five years ago. She started volunteering 12 years ago with an Islamic NGO where she performed various types of volunteering work such as humanitarian, Islamic preaching, and spiritual guidance. She had also co-founded a mental health NGO which focuses on mental health awareness and advocacy. Now, she is employed at another mental health NGO.

AS is a single 26-year-old lady with bipolar disorder who was diagnosed three years ago. She started volunteering in school where she joined an Islamic NGO. Later, she joined another NGO which focuses on humanitarian work in Malaysia and abroad as one of its board members. Other than that, she also advocates for mental health awareness and shares her experience as a PWMI spokesperson in various programs. Today, she is unemployed and still volunteers at the NGO.

KS, a single, 29-year-old woman had been diagnosed with social anxiety disorder about five to six years ago. Her involvement in volunteering began at university. After graduating, she joins several NGOs and volunteers as a committee member for various events and conventions. Other than that, KS also volunteers for humanitarian causes and mental health awareness. Now, she works as a home tutor and volunteers in her spare time.

Zatie is a single 20-year-old lady who was diagnosed with depression in 2018. She started volunteering in high school. Recently, she joined a mental health NGO as a volunteer for mental health awareness. Today, Zatie is pursuing her degree at a local university while continuing to volunteer with the NGO.

Mika is a married 42-year-old woman who had been diagnosed with mental illness since 2007. Her diagnosis had changed over the years and the latest one is depression with psychosis and anxiety. She started volunteering as an informal peer supporter in online support groups in 2014. Later in 2017, she joined a mental health NGO as a peer supporter and crisis team member. Now, she is a housewife and still volunteers in her spare time.

Zainab, a 31-year-old single lady had been diagnosed with bipolar disorder since 2018. She started volunteering a few years ago and now volunteers actively at a mental health NGO. She helps the NGO with events, administrative work, and supporting other PWMI as a peer supporter. Today, she is currently unemployed while still actively volunteering.

### **Data Analysis**

The audio data were transcribed and transcripts were checked twice against the audio recordings for accuracy. Afterwards, the transcripts were imported into QSR NVivo 10 for thematic analysis. Portions of the texts were then segmented into categories, which were derived based on the ideas that are most frequently repeated by the informants. Then, the categories were refined into a term or code that best represents the idea behind them. Next, the codes were compiled into a Microsoft Word document for review. Redundant and overlapping codes were removed, and potential themes began to emerge at this point. Next, the remaining codes were grouped into several themes that shared a common idea based on the research question. The themes were reviewed thrice and compared against the current literature before finally being defined and named.

To ensure the validity, reliability, and trustworthiness of these findings, the triangulation method was implemented which includes member checking, literature review, and expert review.

Transcripts of the interviews were e-mailed to informants and they were given the opportunity to revise or remove any parts of the transcripts. Only one informant asked for the removal of a small part of her transcript which revealed a personal detail that does not affect the data. The findings were also compared with the current literature on this topic in order to determine their validity. Finally, the results and analysis were reviewed by two experts in volunteerism.

## **FINDINGS**

The following paragraphs present the results pertaining to the research question, which is “What are the lived experiences of PWMI in formal volunteering?” The interviews aim to answer this question by asking the informants about their volunteering experience. Based on the lived experiences shared by the informants, findings revealed two distinct themes. Firstly, the informants shared that they have gained various psychological benefits from this activity. The benefits include finding volunteering as therapeutic, volunteering as a productive activity, and gaining self-satisfaction. Secondly, despite the positive experiences, they also reported having negative experiences in volunteering. These were divided into two subthemes, which are challenges and barriers. The challenges in volunteering as a PWMI include burnout, relapse, and triggers, while the barriers that had been identified are lack of family support and stigma. However, even though both positive and negative experiences have been identified, the majority of them agreed that overall, they have more positive experiences than negative ones from volunteering.

### ***i. Psychological Benefits of Volunteering***

The informants described how volunteering is therapeutic, helps them feel productive, and gives them a sense of self-satisfaction. The majority of the informants feel that volunteering is therapeutic as it helps them cope with their illness. For example, Nur shared that volunteering is part of her coping mechanism to keep herself stable. She elaborated:

*“... it is part of therapy, part of my coping mechanism, one of the ways that I use to keep myself stable is by joining programs, activities (...) Because to me, mental illness is not just about our thinking but also our lifestyle, our way of life. So when we participate in society through volunteering work, that thing builds our soul, character, and teaches us to be more understanding, empathic, (...) it can help change our perspective towards life and our perception towards ourselves.” (Nur)*

Nur’s viewpoint is agreed by AS who struggles with suicidality. The excerpt below explains how volunteering gives her life meaning and hence, a reason to keep living:

*“For me, I feel like I have to continue volunteering as long as I live because when I do it, I feel motivated to live. Because if I don’t do it, I would feel like, “What is the point in living?” (...) So when I join volunteering programs, it gives me a reason to live (...) [I keep questioning] why every time I had a suicidal thought, am I still not dead? Maybe God hasn’t allowed me to die yet because I haven’t finished helping others.” (AS)*

The concept of “healing through helping” was also dominant. For Zainab, volunteering helps to rebuild her self-esteem because it gives her a purpose in life. She elaborated:

*“...people say [that] charity is a good way of healing. So, that’s when I started to be like, in hope of helping others, I could help myself as well. Yeah, and it’s kind of like, I supposed that’s how God plans (...) it was then to help myself to give some sort of a purpose to build back my self-esteem and now I’m more motivated to help people.” (Zainab)*

Several of them also mentioned that it feels alleviating to know that they have contributed positively to someone's life through volunteering. Mika explained:

*"So when I help other people, my depression is actually not that severe anymore. It's like, once [in] a while I do get depressed still, but it's just that the severity is not that high because after helping people, after volunteering, by the end of the day I would know that I did something good. I helped someone." (Mika)*

Furthermore, the informants also described volunteering as a productive activity that keeps them occupied and busy. In the excerpts below, some of them attributed this to their preference to keep an active lifestyle:

*"...I don't like to leave my days or weekends empty [without any programs]. [If I find any volunteering programs.] I would immediately apply and join." (Nur)*

*"...maybe I'm the kind of person who doesn't know how to sit still. (...) I mean, I like to do something instead of doing nothing, and I prefer to step into the society instead of just staying at home." (Nurin)*

The concept of "being busy" is also attributed by some informants to having a meaningful activity that resembles a job or occupation. This is especially dominant among the informants who spend long hours volunteering at the NGO and performing multiple kinds of tasks, including administrative work. Even though they were not paid, they still consider it as a significant work, quoting:

*"...right now is at a point where I kind of see it almost like a job, except that we don't get paid [laugh] (...) I know that societal standards define job as a 9-5 and something that gives you money. (...) [but], you cannot disregard this volunteering work. I mean if you cancel out "volunteering", it's still "work" at the end, isn't it? [laugh]. So, what I mean is that it's important for me so that I don't feel useless. Just because I don't get paid by it, that this is not significant work that doesn't contribute to society." (Zainab)*

In addition, they also feel that volunteering prevents them from engaging in harmful coping mechanisms or unproductive activities. For example, AS noted that she does not think about her illness as much anymore since being busy with volunteering programs. She continued to explain that this is because she is always surrounded by other people:

*"To me, that's one of the benefits, it's good lah because those who have mental illness can't be alone. If they're alone, they'll be even more inclined to follow whatever they feel, like hallucinations or whatever. So when they're surrounded by other people, they'll be distracted from constantly thinking [about their illness]." (AS)*

Lastly, most of the informants reported that they get a sense of self-satisfaction when volunteering. It makes them feel good and relieved from the burdens of their illness. For Kay, she felt that volunteering makes her feel fulfilled with her life because she has "devoted a lot of time for it". As for KS, volunteering helps to relieve her from her symptoms. She considers it as a good progress, even though the effects of relief only lasts for a short while. She elaborated:

*"Even if I could get a little bit of progress in healing myself, that would make me so happy. Because even though [the journey to healing] is still far, still difficult, but once in a while I could get that*

*feeling, like “Oh, so this is how it feels like to not having depression on anxiety.” I’d feel so relieved, like “Ah, this is what I wanted.” (...) I still want to feel it, even just for a fleeting moment.” (KS)*

Seeing the positive impacts that they have made on other people through volunteering also gives them a sense of self-satisfaction. Zatie explained:

*“...the best moment is when I could see them grow, see the growth in them. For example in mental health [cases], before this they were so depressed, but after receiving my support, help, and guidance, they are now in the recovery phase (...) When they tell me how happy they are because I have helped them, (...) that makes me so happy.” (Zatie)*

## **ii. Challenges in Volunteering**

Interestingly, despite the psychological benefits, the act of volunteering itself may cause adverse effects on mental illness. These were classified under the subtheme ‘challenges’ and include: burnout, relapse, and triggers.

Firstly, burnout seems to be one of the main challenges the informants faced in volunteering. For example, the symptoms of mental illness itself could lead to burnout like what Nur, who was diagnosed with bipolar disorder, has experienced:

*“...I don’t know how to balance my energy. I have bipolar, so when I went all out outside, I would come home feeling exhausted (...) I would absorb the energy around me, I would feel extremely happy (...) So when I come home, I would feel exhausted [because] my energy had been depleted. So yeah, I don’t know how to balance that yet.” (Nur)*

The causes of burnout can be complex for PWMI, as reported by the informants. For Yasmin, who volunteers as a peer support facilitator at the mental health NGO, it is her passion in mental health advocacy that has driven her towards burnouts. According to her, she felt pressured to exert herself to spend more time and effort in volunteering work, to the point of neglecting her own needs. She explained:

*“...if I don't think of myself as a professional [social worker], it's very, very easy to just keep on continuing giving and giving and giving, and it reaches a burnout state and at that point it's very hard. It takes a longer time to recover. (...) I think that's the initial part of the burnout, where you start feeling guilty for having these symptoms. (...) And that guilt manifests differently when you're in this space because you start feeling like you need to do more because this is a space that's very near and dear to you and people's lives are at stake. And also having gone through the darkness alone before, and having a deeper, higher sense of purpose to get the work done, it's easier for your symptoms to manipulate that guilt in even like a sense of shame so that you ignored self-care in order for you to do the work.” (Yasmin)*

Other than burnouts, the majority of the informants also struggle with relapsing when volunteering. When their symptoms reappear, it would disrupt their volunteering work and cause a lot of troubles with other volunteers or organizations. The excerpts below demonstrate how relapsing would force them to stop doing their volunteering work and its ugly consequences:

*“...my problem is, [I find it] hard to manage. Let’s say [when] I’m in the depressed phase [and feeling] down, I will stop everything and will not do anything at all. In terms of the ups and downs of my mood, sometimes I myself don’t know how it happened.” (Unais)*

*“...when depression hits, that’s the hardest part (...) You just don’t feel like doing anything. You just feel like lying [on the] bed and do nothing. At that time, I would get scolded by others, “What’s wrong with you? You don’t want to do your part?” (...) So in a way it affects my work too (...) the mind keeps on doubting (...) It’s not like you’re being negative but you think of thousands of possible outcomes (...) It’s crazy hard to control it.” (KS)*

Relapsing often leaves the informants feeling guilty as they feel like a burden to others, yet unable to control or improve the situation. They shared:

*“...[once], I had to be warded [and] I couldn’t proceed with the program, so I felt guilty with the organizer. Because they have had everything planned and suddenly I had to cancel. And [the news of] cancellation came from the doctor, not from myself. So, I felt guilty but the doctor would not release me from the ward. So that is one of the challenges.”(Nurin)*

*“...in the early stages of volunteering, it’s normal for you to get a bit upset. Upset in the sense of when you have high hopes, like you want to help someone. You go volunteer, then suddenly you feel like you relapse, (...) so you feel as if you’re useless. You are burdening other people who are volunteering.” (Mika)*

Lastly, doing volunteering work and being in the community would expose the informants to various factors that could trigger them. Within the context of mental illness, a trigger refers to any event, person, sensation, or thing that cause symptoms to resurface. KS, who was diagnosed with social anxiety, described how exposing herself to social situations while volunteering would sometimes trigger panic attacks. She shared:

*“...because I want to release myself from this illness, right? So, one of the challenges is that before I join a program, I thought that I could do it. But when I’m there, that was when I realized that it was actually really hard, because in that situation, I’d suddenly feel panicked, my palms were sweaty, or I’d suddenly feel like crying. Or sometimes I have meetings to attend, but I’d feel like I want to find a thousand excuses to not join (...) So those things make me feel like, ‘Oh, I want to be a hermit, I don’t want to meet anyone today.’ (...) at that time, I’d feel the anxiety, the palpitation. My heart would race so fast, and I’d feel like crying right there and then.” (KS)*

Conflicts or negative attitudes among other volunteers could also become a trigger. For AS, seeing people quarrel at the NGO could trigger her symptoms:

*“I can’t meet people who like to raise their voices or cause troubles or like to annoy others. It’s hard for me (...) Because I don’t like to be in a situation where I have to watch people quarrel. Means fighting or raising their voices (...) Usually when other members are not on the same page, that could lead to fights.” (AS)*

### **iii. Barriers in Volunteering**

Barriers refer to external factors that make it difficult for the informants to participate in volunteering activities. Two barriers were identified from the interview, which are lack of family support and stigma.

Lack of family support is one of the strongest themes in terms of barriers, especially in the beginning of their volunteering participation. For Nur and KS, their families were reluctant to see them going out to attend volunteering programs during the weekends due to the perception of them

not spending enough time with their family, being ‘busy’, and ‘always away’. However, they become more supportive after a while, quoting:

*“At first, when I first started volunteering, it occupied my weekends. So during weekends, I’d be away from home due to volunteering, then on Monday till Friday I’d be at work. So my parents commented that I am always outside and missing from home (...) So in the beginning, they didn’t really support me because I’m always away. But now they’re okay with it.” (KS)*

Meanwhile, for AS, the support seems partial where her siblings are supportive but her parents are sometimes supportive and sometimes not. As for Kay, her family considers volunteering as a waste of time because there is no financial benefits:

*“...they think volunteering is something like wasting of time because you get no money [despite spending] a lot of time.” (Kay)*

Another barrier that is worth mentioning is stigma, which was brought up by Unais. He reported having to face stigma in his NGO due to his diagnosis. He finds it difficult because people struggle to understand his mental health condition. However, when some of them tried to understand him, his symptoms would worsen and made him incline towards suppressing himself. He explained:

*“When stigma exists, it makes it a bit difficult for me to advance myself. So the barrier is due to stigma (...) Sometimes they try to understand, but instead, that becomes a factor for me to suppress myself. It makes me feel more depressed, tired, more anxious.” (Unais)*

Based on the insights shared by the informants in this study, even though both positive and negative experiences have been identified, the majority of them agreed that overall, they have more positive experiences than negative ones from volunteering.

## **DISCUSSION**

Interviews with the 10 informants revealed that volunteering is a mixed experience for PWMI where they not only gained psychological benefits, but also faced various obstacles and barriers. The informants unanimously agreed that they have gained numerous psychological benefits from volunteering, which is congruent with the themes in the recovery literature (Pérez-Corrales et al., 2019; Provencher & Keyes, 2011). Some of them described volunteering as being therapeutic as it helps to reduce the severity of their symptoms and keeps them stable. This finding aligns with the research by Myers et al. (2016) who suggested that performing meaningful activities like volunteering helps PWMI to achieve stability. Similarly, Yeung et al. (2017) reported that volunteering may help to reduce the symptoms of depression, which confirms the findings of this study. Findings also suggest that volunteering keeps the informants productive and provides them a sense of self-satisfaction. According to Fegan (2014), this could be due to the attainment of a new role as a beneficial and contributing member of society. In line with this, Juliana Rosmidah Jaafar et al. (2019) also supported the idea by suggesting that involvement in voluntary activities could enhance positive image in an individual’s networks.

Participation in volunteering programs is not only beneficial for PWMI, but may also pose negative impacts on their recovery process. This finding supports previous studies which reported stress, stigma, and discrimination as some of the negative impacts faced by PWMI volunteers (Farrell & Bryant, 2009; Read & Rickwood, 2009). Our findings suggest that burnouts could be caused by their own symptoms and difficulties in balancing priorities. This is congruent with the research by

Allen and Mueller (2013) who found that burnout is a common phenomenon in volunteering work among the general population. However, the causes of burnout found in this study differ from Allen and Mueller's who suggested lack of voice and role ambiguity as the contributors to burnout. These contrasting findings could be due to the unique needs of PWMI which are influenced by their illness and recovery process. Other challenges found in this study that are unique to PWMI are relapse and triggers, which is supported by previous studies. For example, Thomas et al. (2019) found that relapse among people with schizophrenia would hinder them from keeping their jobs as they would either resign or were fired due to it. In the same vein, Sweeney et al. (2018) reported that PWMI often had experienced some sort of trauma in the past, thereby making them prone to be triggered by interpersonal conflicts that may resemble past traumatic experiences.

The informants experienced several barriers in volunteering. Some reported that their families are not very happy to see them volunteer. This finding is consistent with research by Haug and Gaskins (2012) and Kramer et al. (2013) which reported that conflicts with family roles or schedules can negatively impact volunteering motivation and participation. Family support is crucial for PWMI because their illness may cause difficulties for them to access volunteering opportunities, hence the need for extra encouragement and support from their loved ones. Another barrier reported by the informants is being stigmatized by other volunteers in the organization. Despite stigma being one of the most widespread barriers for PWMI in all contexts (not just in volunteering), only one informant reported experiencing it in the volunteering context. This could be due to the fact that this informant only volunteers at a non-mental health NGO, which may expose him to individuals with low awareness of mental health. For the general population, social support from significant networks is crucial in supporting individual well-being and self-development (Dong & Siti Maziha Mustapha, 2018). This could also be applied to specific groups such as people with special needs and disability and therefore, underscores the importance of an environment that is supportive of PWMI in NGOs and nonprofit organizations.

With regards to the mixed experience, this finding supports previous studies which suggest that volunteering may not only promote benefits but also has adverse effects for PWMI. For example, Read and Rickwood (2009) reported the benefits and negative experiences of volunteers with mental illness who advocate as consumer educators. Similarly, Farrell and Bryant (2009) suggested that volunteering may promote social inclusion and social exclusion simultaneously for PWMI through occupational apartheid. This mixed experience could be due to the fact that PWMI are often considered as having lower social status or value, which causes them to be treated unfairly and being denied opportunities. Nevertheless, involvement in diverse settings could be seen as a potential platform for positive interaction and hence, should be encouraged for this population (Norzita Yunus et al. 2016).

## **LIMITATIONS**

Three limitations apply to this study. Firstly, the data collected and analyzed was limited to saturation and the research objective only. Therefore, the findings may not be able to explain the phenomenon of volunteering among PWMI beyond the boundaries of the research question. Secondly, samples in this study only represent PWMI from specific mental disorders only and therefore, the findings may not resonate with all PWMI who are involved in volunteering. Lastly, the results are limited to the types of NGOs that were represented by the informants, which means that different results may possibly be achieved should the samples represent different types of NGOs.

## **CONCLUSION AND RECOMMENDATIONS**

This study aimed to explore the lived experiences of PWMI who are involved in formal volunteering activities. Findings revealed the pros and cons of formal volunteering for this population. The informants unanimously agreed that they have gained psychological benefits from this activity, which supports their recovery process. However, setbacks that are related to their mental illness were also reported, which underscores the need to provide a supportive environment that could enhance their experience and promote sustainability and prolonged engagement in volunteering. Furthermore, actions should be taken to prevent the barriers that may hinder them from participating in volunteering programs.

This study contributes to two major areas. Firstly, in the body of knowledge on volunteerism, this study extends the knowledge to a particular group of people, which is PWMI. Prior to this study, there is a paucity of research on the participation in volunteering among PWMI in a local setting. Therefore, findings from this study contribute to the understanding of the benefits, barriers, and challenges of volunteering among PWMI. Secondly, this study contributes to the body of knowledge on psychosocial interventions for PWMI in a local setting. Prior to this research, the bulk of literature on PWMI in Malaysia revolves around biomedical interventions. Although studies on psychosocial interventions exist, there is a lack of research on volunteerism as occupational therapy for PWMI. Findings from this study have demonstrated that volunteering may promote social inclusion and recovery by helping them feel productive, giving a sense of healing, as well as a sense of self-satisfaction.

Findings from this study revealed that lack of family support and stigma may pose as barriers that may prevent PWMI from volunteering. Therefore, families of PWMI and the community must be educated on the importance of involvement in socially inclusive activities like volunteering to encourage their participation. Furthermore, this study found that mental illness itself may disrupt the volunteering involvement of PWMI through burnouts, triggers, and relapses. Therefore, NGO members should be informed of these possible disruptions. A module guideline on how to support PWMI volunteers during times of crisis (e.g. burnouts, triggers, and relapses) should be drafted by policymakers through strategic collaboration. This may include the Department of Social Welfare, Ministry of Health, Ministry of Women, Family and Community Development, and Registrar of Societies. Inputs from various perspectives are crucial to produce a holistic and trauma-informed module that addresses the different needs of PWMI, which will eventually help to guide the NGOs in supporting PWMI's involvement in volunteering. NGOs should also be encouraged to be socially inclusive of PWMI in their volunteering programs. To do this, the government could provide incentives to the NGOs that are socially inclusive and adhere to the module guideline.

Additionally, findings from this study may help guide mental health professionals in designing psychosocial intervention programs for PWMI, such as supported volunteering. Current interventions are missing the insights from PWMI themselves, which may hinder their effectiveness and prevent successful recovery. With the inputs from this study, such programs would be more in tune with the needs of PWMI and align with their aspiration for holistic recovery. Collaboration between mental health practitioners and NGOs could also be helpful in preparing a safe and supported environment for recovery.

To better understand the implications of these findings, future studies could expand the study settings to include PWMI from different localities and not just the state of Selangor. The insights from PWMI volunteers from other localities could possibly support the findings from this study, as well as reveal different perspectives and therefore, would paint a richer picture on this under-investigated topic. Additionally, future studies should also consider investigating the prevalence of PWMI in volunteering activities. Data on this prevalence could help the policymakers and mental health professionals in strategizing their efforts to encourage more participation in volunteering among PWMI.

In conclusion, this study has provided insights on the lived experience of PWMI who participate in formal volunteering. Prior to this study, the voices of PWMI were missing from the social and health policies in Malaysia with regards to their needs to achieve full participation in the society. The findings from this study support the potential of volunteering as an effective psychosocial intervention for PWMI to encourage social inclusion and therefore, promote holistic recovery. The results may inform policymakers, mental health professionals, social workers, as well as NGOs on the significance of volunteering in the recovery process of PWMI, as well as guide them in designing supported volunteering programs that encourage social inclusion.

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