

Recovery among People with Mental Illness (PMI) as Perceived by the Caregivers in Islamic Boarding School (IBS) in Indonesia

Widodo Sarjana¹, Alifiati Fitrikasari², Sri Padma Sari³

ABSTRACT

Background: Mental hospitals as places to rehabilitation people with mental illness (PMI) in Indonesia are limited in numbers and do not meet with the number of PMI. The society may contribute in facilitating recovery and rehabilitation place for PMI including Islamic boarding school. Some Islamic boarding schools provide rehabilitation for PMI to help with recovery process. Recovery is an important aspect to assess the success of PMI rehabilitation. Nevertheless, there has been no study on Islamic boarding school's caregivers' perception on PMI recovery.

Purpose: This study aims to explore recovery perception of caregivers treating PMI in Islamic boarding school and factors affecting recovery.

Methods: Data are acquired from 19 caregivers from three Islamic boarding schools providing rehabilitation for PMI with Focus Group Discussion (FGD). The data analyzed using descriptive analysis.

Result: Having a good communication is a recovery criterion that is mentioned the most by caregivers. There are three biggest factors affecting recovery based on the caregivers such as prayers or religion followed by social support from family and environment and also doing activities.

Conclusion: The results may depict the PMI recovery so that the health care providers can provide interventions that can support the recovery process in PMI.

Keywords: people with mental disorders, recovery, caregivers, islamic boarding school

¹ Psychiatric Department, Faculty of Medicine, Diponegoro University, Indonesia.
Email: widodosarjana22@yahoo.com

² Psychiatric Department, Faculty of Medicine, Diponegoro University, Indonesia.

³ School of Nursing, Faculty of Medicine, Diponegoro University, Indonesia.

BACKGROUND

Prevalence of mental disorders including severe disorders such as schizophrenia and emotional mental disorders are considered high in Indonesia. Based on national basic health research 2013, nation-world wide prevalence of emotional mental disorder is 6% while severe mental disorder is 1% (Basic Health Research, 2013). In Central Java the number of mental disorders has increased from 2007 to 2011 from 0.49% to 7.18%. Data in the Regional Mental hospital (RMH) Dr. Amino Gondohutomo Semarang mentioned that the number of inpatients is 3.914 persons with 99% suffering from schizophrenia and emotional mental disorders (Lukitasari & Hidayati, 2013).

People with mental illnesses have some symptoms as a form of mental disorder such as psychosis (hallucination and delusion), speech disorder, loss of motivation and cognitive disorder. Some of those symptoms may cause social and work dysfunctions, lack of interpersonal relationship, decline in personal care and mortality or morbidity (Moller, 2009; Townsend 2008). Individuals suffering from this disorder also suffer from a second disease, from social environment reaction and stigma. The society often label "crazy people" making PMI feel ashamed to the society, have low self-esteem and the absence of hope. The impact of stigmatization will result in social isolation, lack of opportunity such as in job opportunity and social discrimination of PMI (Horrison & Gill, 2010). All of these may reduce the quality of life of PMI. Some people with mental illnesses also suffer from "pasung" (physical restraint) because family or society feel disturbed with their presence.

Therapies for PMI can be divided into two therapies, pharmacological and nonpharmacological therapy. The pharmacological therapy such as antipsychotic agents is effective in alleviating symptoms in schizophrenia such as hallucination, delusion, speech and inappropriate affect (Moller, 2009). While the nonpharmacological therapy or psychosocial therapy in schizophrenia are psychoeducation, cognitive behavior therapy (CBT), social skills training (SST), family therapy and assertive community treatment (ACT) (Tandon, Nasrallah, & Keshavan, 2010). Psychosocial therapy has some benefits such as relieving symptoms, preventing relaps, increasing social and self-care functions and quality of life in people with schizophrenia. Both modalities of therapy are aimed at helping the recovery of PMI.

Recovery is an important aspect to the success of the treatments of PMI. Recovery is a unique process in each individual. Recent studies stated that the definition of recovery is divided into clinical recovery and personal recovery. *Clinical recovery* is a low level of psychopathology or decline in symptoms of mental disorders (Bobes et al, 2009) and no rehospitalization (Grossman et al., 2008). Meanwhile, social recovery is defined as presence of hope and meaningful purpose (Hoper, 2007; Lysaker et al., 2010), happiness (Buckland, Schepp, & Crusoe, 2013), socialization and finding place in the society and being involved in a job (Cavelti et al., 2012; Roe, Mashoach-Eizenberg, & Lysaker, 2011; Silverstein & Bellack, 2008).

Rehabilitation for PMI plays an important role in helping the recovery process. Rehabilitation is an interventional program to prevent or reduce the severity of the mental disorders in need (Perese & Wu, 2010). The government has responsibilities in

providing rehabilitation care in order to help PMI recovery based on Regulation No. 36 year 2009 about health clause 145 (Konas Jiwa, 2013). However, psychiatric hospital (PH) as a rehabilitation place for PMI is limited in number and do not meet with the number of people with mental disorders which is increasing through the years.

Islamic boarding school (IBS) is a place to learn the religion of Islam which is growing and expanding in Indonesia because of enormous supports and hopes from the society. Some IBS do not only function as a place for the students to learn but also contribute in facilitating recovery and rehabilitation place for people with mental illness. Some studies showed that rehabilitation in IBS is beneficial in helping recovery along with religious activities done in IBS (Sari & Wijayanti, 2014). However, during the course there are some problems affecting the PMI rehabilitation in IBS such as the lack of care giver, therapies provided, the minimum budget and the lack of society and family support (Dahliyani, 2012; Naufal, 2014).

Recovery is a crucial aspect for people with mental disorders especially to offer positive impact on the quality of life. The caregivers are the person who responsible to the development and recovery for PMI in IBS replace the role of caregiver when the PMI lived with the family. Nevertheless, study on PMI recovery according to IBS' caregivers has not been done in Indonesia. Thus, the purpose of the study is to get overview of the definition of recovery and factors that may help the recovery process according to the caregivers treating PMI in IBS.

OBJECTIVE

The objective of this study is to explore recovery perception of caregivers treating PMI and factors affecting recovery perceived by the caregivers in Islamic boarding school in Indonesia.

METHODS

Study design

This study is a qualitative research with fenomenology method meaning that a study has the purpose of depicting and analyzing. With this method, the authors may understand about PMI recovery perception according to the caregivers and factors affecting recovery.

Sample and setting

This study conducted at three boarding schools in Demak, Magelang and Yogyakarta which provided rehabilitation among PMI. Participants in this study are caregivers treating PMI in IBS. Inclusion criteria for the participants are (1) caregivers who are responsible for treating PMI, (2) living in Islamic boarding school and (3) are willing to participate in this study.

Ethical Considerations

This study had been approved by the ethic committee from Faculty of Medicine Diponegoro University. The informed consent was obtained from all patients. Informed consent is provided for the participants to gather information in the study, the right to participate and the confidentiality guaranteed by the researchers including anonymity.

Data collection and analysis

Data collection is used by the questionnaire about personal identity, and Focus Group Discussion (FGD). The authors then use descriptive analyses to thoroughly review the significant results.

RESULT

Characteristics of the participants

There are 19 caregivers from three Islamic boarding schools. The description of participants' characteristics can be seen in table 1.

Table 1. Participants' characteristic

No.	Name (Initial)	Age	Sex	Level of education	Length in boarding (Month)	Length in caring (Month)
1	M	18	F	Junior high school	24	18
2	AA	23	M	Senior high school	72	36
3	N	18	M	Senior high school	48	1
4	RCM	16	M	Junior high school	24	12
5	MNK	16	F	Junior high school	11	1
6	UC	16	F	Junior high school	36	1
7	MI	17	M	Senior high school	24	1
8	RA	23	M	Senior high school	60	1
9	SN	18	F	Senior high school	48	1
10	SF	17	F	Junior high school	36	6
11	NF	19	F	Senior high school	36	1
12	AK	28	M	Bachelor	48	36
13	YP	28	M	Senior high school	84	24
14	TAR	22	M	Senior high school	96	3
15	IU	24	M	Senior high school	48	24
16	MA	27	M	Senior high school	60	8
17	MS	23	M	Senior high school	84	3
18	RR	23	F	Junior high school	30	4
19	FF	25	F	Junior high school	96	12

Recovery

According to the participants, there are some criteria when PMI is said to recover, as can be seen in the table 2. After living for some time with PMI, caregivers formulate a definition of recovery itself. Some caregivers assume that patients are said to recover when they talk appropriately and act like normal people.

Table 2. Criteria of recovery

No	Criteria of recovery	N	%
1	Good communication	15	78.9
2	Normal attitude	10	52.6
3	Good relationship	3	15.8
4	Good behaviour	3	15.8
5	Good orientation	3	15.8
6	Having activity	3	15.8
7	Socialisation	2	10.5
8	Having no hallucination	2	10.5
9	Having goal of life	2	10.5
10	Nonadherence to medication	2	10.5

This is implied from the said of a participant as follows:

“...to recover means being able to comprehend and answer appropriately when being spoken to... when one is not recovered, the answers might not be proper...”

(YP)

“...recovery... can be calm, used to have a weird behavior, smiles and sings on his own... now those are diminished...”

(FF)

Factors affecting recovery

Some factors may affect patients' recovery according to the caregivers, among others can be seen in table 3.

Table 3. Factors contributing to recovery

No	Factors	N	%
1	Praying/ religion	11	57.9
2	Support from family and community	10	52.6
3	Having activity	10	52.6
4	Belief for recovery	5	26.3
5	Medication	5	26.3

There are some factors affecting the recovery according to caregivers such as therapy/prayers, family and environmental support, doing activities, faith to recover and taking medications. These things are stated by an informant as follows:

...religious activity, doing Quran recital, prayer may accelerate recovery.

(AK)

...to recover, factors contributing to it are willingness, from medications to help, prayers given: communal prayers may make us closer and have more faith in Allah.

(RR)

DISCUSSION

Recovery is a unique process in each individual. The definition of recovery in people with mental disorder (PMI) that is found in most studies is being able to communicate followed by behaving like normal person and cooperative. This definition is in line with previous studies referring that recovery is an outcome with low level of psychopathology and severity of the existing symptoms such as speaking and behaving well (Bobes et al., 2009; Silverstein & Bellack, 2008). Some expressed by caregivers also don't meet other criteria i.e. the return of social function like working and absence of rehospitalization (Grossman et al., 2008). This shows that the definition of PMI recovery chosen mostly by the Islamic boarding school caregivers still focuses on the clinical recovery or the low level of psychopathology or lack of symptoms of mental disorder.

Only few caregivers mention that PMI recovery chose the presence of socialization and purpose in life that is a part of a *personal recovery* (Cavelti et al., 2012; Roe, Mashoach-Eizenberg, & Lysaker, 2011). This study was supported by other studies about the concept of recovery as a process to achieve a meaningful life (Hopper, 2007), happiness (Buckland, Schepp, & Crusoe, 2013) or quality of social relationship, self-esteem, and hopes (Lysaker et al., 2010). The study is also supported by Ciudad, Bobes and Alvarez (2011) in his study that recovery in PMI at least meet three different criteria i.e. reduced symptoms, increased function and subjective response in each individual. The lack of symptoms can be obviously seen such as good communication, absence of hallucination or good orientation. Increased function can be seen by socialization and activities while subjective response can be seen by knowing the purpose of life.

Factors affecting recovery according to participants of the study are therapies done by the Islamic boarding school such as prayers, family and environmental support, doing activities, faith to recover and taking the medications. Some caregivers in Islamic boarding school believe that therapies and supplications given to PMI while living in Islamic boarding school contribute hugely to recovery process of PMI. This agrees with other studies done in Islamic boarding school that is Dahliyani (2012) exploring methods and religious activities done in Islamic boarding school to PMI. The result showed that religious activity done in Islamic boarding school for PMI such as congregational prayers, Quran recital, review about wisdom stories, communal supplications, remember of God's messenger, studying and individual mentoring. The main therapy applied is, among others, supplications and proven effective on PMI recovery.

Besides, supplication is a part of spirituality which is beneficial for PMI recovery. This is in line with previous studies done by Sari and Wijayanti (2014) which attempted to explore spiritual experience of PMI and benefits while living in Islamic boarding school. The results were: 1) spiritual definition of being close to Allah and religious activities which become increasingly consistent, and 2) benefits of spirituality i.e. recovery from mental illness, symptoms management, behavioural change, emotional change and attention for the future. Spirituality plays an important role for patients including helping recovery of PMI.

Some caregivers also choose family and environment support as an important influence to affect the PMI recovery while living in Islamic boarding school. Some caregivers complain about the lack of family support of PMI. The results are in line with other studies that the low rate of seclusion and the abundant social support may increase recovery and quality of life of PMI (Roe, Mashoach-Eizenberg, & Lysaker, 2011).

The results of this study show that therapy, supplications etc play more important role compared to medications. This contradicts the previous studies in other countries stating that medication compliance and types of medications given are predictors for recovery (Novick et al, 2009). Some Islamic boarding schools in Indonesia providing rehabilitation for PMI do not utilize medications in the treatment of PMI similar to previous studies done in IBS but only using therapies and prayers which are considered beneficial for the PMI recovery process (Dahliyani, 2012; Nusrotuddiniyah, 2013).

CONCLUSION

The study reflects recovery perception people with mental illness (PMI) according to caregivers treating PMI in Islamic boarding school. Most caregivers consider PMI recovery has some characteristics, with top three characteristics as follow: being able to communicate well followed by behaving like normal people and is cooperative. Meanwhile factors affecting recovery according to IBS' caregivers are prayers, family and environmental support, doing activities, faith to recover and taking medications. There are three themes acquired from this study that is spiritual definition, spiritual experience and its effect.

The result of the study recommends that mental health care providers may discuss regarding education about mental illness to IBS' caregivers considering there are IBS in Indonesia that provide rehabilitations for PMI. Besides, health care providers and/ or psychiatric hospital are expected to provide spiritual therapy and facilities for PMI's spiritual improvement because supplications and spiritual condition may help with PMI recovery process.

PMI recovery in this study is a perspective of PMI caregivers living in IBS. Therefore, future studies may explore PMI recovery from the perspective of PMI, family or mental health care provider such as psychiatrists and mental nurses. As a result, all elements have the same perception on PMI recovery and proper measures to help with PMI recovery process.

ACKNOWLEDGMENTS

This paper is part of research funded by the Faculty of Medicine, Diponegoro University Indonesia under its Programme Grants for Developments and Applied Research.

REFERENCES

- Basic Health Research. (2013). *Laporan Riskesdas 2013 (Riskesdas report)*. Retrieved on March 25 2014, from www.litbang.depkes.go.id/sites/.../rkd2013/Laporan_Riskesdas2013.PDF
- Bobes, J., Ciudad, A., Alvarez, E.,... et al. (2009). Recovery from schizophrenia: Results from a 1-year follow-up observational study of patients in symptomatic remission. *Schizophrenia Research*, 115, 58–66.
- Buckland, H. T., Schepp, K.G., & Crusoe, K. (2013). Defining Happiness for Young Adults With Schizophrenia: A Building Block for Recovery. *Archives of Psychiatric Nursing*, 27, 235–240.
- Cavelti, M., Kvrjic, S., Beck, E.M...etal. (2012). Review Assessing recovery from schizophrenia as an individual process. *European Psychiatry*, 27, 19–32.
- Ciudad, A., Bobes, J., Alvarez, E,...et al. (2011). Clinical meaningful outcomes in schizophrenia: Remission and recovery. *Rev Psiquiatr Salud Ment (Barc.)*, 4(1),53–65.
- Dahliyani, I. (2012). *Pembinaan keagamaan pada santri panti rehabilitasi sakit jiwa dan narkoba di Pondok pesantren Maunatul Mubarak, Sayung-Demak (Religion treatment to the rehabilitation at islamic boarding school Maunatul Mubarak, Sayung, Demak)*. Retrieved on November, 12, 2014, from perpus.iainsalatiga.ac.id/.../b95c1a194870ff95.pdf
- Dominguez, M., Viechtbauer W., Simons C.J., van Os, J., & Krabbendam, L. (2009). Are psychotic psychopathology and neurocognition orthogonal? A systematic review of their association. *Psychology Bulletin*, 135, 157-171.
- Grossman, L. S., Harrow, M., Rosen, C...et al. (2008). Sex differences in schizophrenia and other psychotic disorders: a 20-year longitudinal study of psychosis and recovery. *Comprehensive Psychiatry*, 49, 523–529.
- Harrison, J., & Gill, A. (2010). The experience and consequences of people with mental health problems, the impact of stigma upon people with schizophrenia: A way forward. *Journal of Psychiatric and Mental Health Nursing*, 17, 242–250.
- Hopper. (2007). Rethinking social recovery in schizophrenia: What a capabilities approach might offer. *Social Science & Medicine*, 65, 868–879.
- Konas Jiwa. (2013). *Proceeding Konas Jiwa XI*. Kaltim: IPKJ.
- Lukitasari, P & Eni Hidayati, M.K. *Perbedaan Pengetahuan Keluarga tentang Cara Merawat Pasien Sebelum dan Sesudah Kegiatan Family Gathering pada Halusinasi dengan Klien Skizofrenia di Ruang Rawat Inap Rumah Sakit Jiwa Daerah Dr. Amino Gondohutomo Semarang (Differences of Family knowledge in caring the patient before and after family gathering activity among schizophrenia patients with hallucination inpatient psychiatric hospital)*. *Keperawatan Jiwa*,1, 18–24.
- Lysaker, P. H., Ringer, J., Maxwell, C,...et al. (2010). Personal narratives and recovery from schizophrenia. *Schizophrenia Research*, 121, 271–276.
- Mohr, S, Perroud, N., Gillieron, C., Brandt, P., Rieben, I., Borrás, L., & Huguelet, P. (2011). Spirituality and religiousness as predictive factors of outcome in schizophrenia and schizo-affective disorders. *Psychiatry Research*, 186, 177–182.

- Moller, M. D. (2009). Neurobiological responses and schizophrenia and psychotic disorders. In G. W. Stuart, & M. T. Laraia (Eds.), *Principles and practice of psychiatric nursing* (8th ed., pp. 386-422). Philadelphia, PA: Mosby.
- Naufal, A. A. (2014). *Proses interaksi sosial dalam rehabilitasi pasien gangguan jiwa* (*The process of social interaction in rehabilitation of patients with mental illness*). Retrieved on November, 12, 2014, from repository.unej.ac.id/.../Aditya
- Novick, D., Haro, J. M., Suarez, D., ... et al. Recovery in the outpatient setting: 36-month results from the Schizophrenia Outpatients Health Outcomes (SOHO) study. *Schizophrenia Research*, 108, (2009), 223–230.
- Nusrotuddiniyah. (2013). *Terapi Sufistik: Studi tentang penyembuhan penderita gangguan jiwa di ponpes az-zainy Malang* (*Sufistic therapy: study about recovery in people with mental disorders*). Retrieved on 12 November, 2014, from 2014.<http://digilib.uinsby.ac.id/id/eprint/10950>
- Perese, E. F., & Wu, Y. B. (2010). Shortfalls of Treatment for Patients with Schizophrenia: Unmet Needs, Obstacles to Recovery. *The International Journal of Psychosocial Rehabilitation*, 14(2), 43-56.
- Roe, D., Mashlach-Eizenberg, M., & Lysaker, P. H. (2011). The relation between objective and subjective domains of recovery among persons with schizophrenia-related disorders. *Schizophrenia Research*, 131, 133–138.
- Sari & Wijayanti. (2014). Keperawatan spiritualitas pada Pasien Skizofrenia (Spirituality nursing in people with schizophrenia). *Journal Ners*, 9, 1, 35-40.
- Silverstein & Bellack. (2008). A scientific agenda for the concept of recovery as it applies to schizophrenia. *Clinical Psychology Review*, 28, 1108–1124.
- Tandon, R., Nasrallah, H. A., & Keshavan, M. S. (2010). Schizophrenia, “Just the facts” 5. Treatment and prevention past, present, and future. *Schizophrenia Research*, 122, 1-23.
- Townsend, M. C. (2008). *Psychiatric mental health nursing: Concepts of care in evidence-based practice* (5th ed.). Philadelphia, PA: Davis.