

# **The Lived Experience of Spirituality of Patients with Schizophrenia in Boarding School (Pondok Pesantren)**

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## **ABSTRACT**

Spiritual reported to have benefits for healing and quality of life for people with mental disorders including schizophrenia patients. Spiritual can also be a coping strategy for people with schizophrenia. This study aims to explore the experiences of patients with schizophrenia who lived in the boarding school. This study uses descriptive phenomenological approach. The purposes of this study are (1) describes the spiritual experience that people with schizophrenia get in boarding school, (2) identify their need for spirituality, (3) identify the impact of spiritual experiences of people with schizophrenia who live in boarding school.

Participants in this study who were diagnosed with schizophrenia and live in boarding school and general informants. Data were obtained using indepth interviews with a tape recorder, observations, field notes and photographs. Data were analyzed using descriptive analysis through hermeneutic interpretation.

Three main themes emerge from this study are meaning of spirituality, spirituality experience and the impact of spirituality.

Keywords: schizophrenia, spirituality, lived experiences

## **Background**

Schizophrenia is a common mental illness that affects a large number of persons around the world. Figures showed that 24 million people worldwide were affected by schizophrenia (World Health Organization [ WHO ], 2011) . In Indonesia, according to the Central Statistics Agency, the prevalence of people with schizophrenia was estimated to have increased from 1% to 2% of the population in Indonesia.

Schizophrenia has impact on the individual. Patients with schizophrenia have some symptoms that can lead to social and occupational dysfunction as interference in work or activities, lack of interpersonal relationships, self-care abilities decline and mortality or morbidity (Moller, 2009). Individuals who suffer from this disease also has a second impact from the environment reaction and social stigma. The impact of stigmatization can cause schizophrenia experience of social isolation and lack of life opportunities such as employment and social discrimination as well ( Horrison & Gill, 2010). All of these can reduce the quality of life of this people.

Religion is a broad concept which can be defined as spirituality (which deals with relationships in the form of transcendent and the meaning of life ) and religious (specific behavioral , social , doctrinal) ( Huguelet , Mohr , Borrás , Gillieron , & Brandt, 2006). However, most of studies still rarely considered that religion has an important role as a factor that can influence the outcome of patients with schizophrenia (Mohr et al., 2011). Most of those studies have focused on religious delusions and hallucinations that connects religion with psychopathology of schizophrenia (as cited in Mohr Mohr et al., 2011).

Spirituality is conceptualized as the "essence of human" (Polatajkoetal, as cited in Smith & Suto,2012). Although there is no consensus, many theories understand the meaning of personal spirituality. In addition, personal and community spirituality is defined based on the values, beliefs, experiences, and practices that emerge from the culture of individuals, families and religious communities (Kroker as cited in Smith & Suto,2012).

Some studies suggests that religion and or spirituality is very important for people with chronic diseases, including for people with schizophrenia. Study shows that religion has a relationship with an increase of quality of life. Study in Switzerland with 115 schizophrenia patients showed that 45 % of patients considered that religion is the most important element in their lives, and religion can have a positive effect (for example hope, meaning of life, and purpose of life ) and also negative effects (eg , despair and suffering) ( Huguelet et al., 2011). A study conducted by Shah, Kulhara, Grover, Kumar, Malhotra, & Tyagi (2011) suggested that " religious practices" and the personal beliefs were the predictors of quality of life of people with schizophrenia.

In Indonesia, the majority of the population is Muslim ( 88.1 % ) (Central Bureau of Statistics, 2010). Therefore, Islam has a great influence in community life. Boarding school is the place to study the Islamic religious sciences. There were approximately less than 27.218 boarding schools spread of across Indonesia nation (Islamic Education Statistics 2010/2011 ).

Researchers understand that religion and spirituality are very important for people with schizophrenia primarily to provide a positive impact on quality of life. Therefore, the purpose of this research is to gain an overview of the experience of the spiritual life of people with schizophrenia who live in boarding school.

## **Research Methods**

This research was a descriptive phenomenology. The researcher can understand spiritual experiences in patients with schizophrenia who lived in the boarding school. Giorgi method was used as guideline. The data were collected from interview which can be done in 2 sessions to clarify the data.

The population in this study was schizophrenia patients who live in boarding school. Informants in this study consisted of key informants and general informants. The number of informants in this study considered based on the data, where the data reached saturation, in the sense that no new data were obtained.

The inclusion criteria for the key informants were (1) rehabilitant who have a diagnosed of schizophrenia, (2) more than 18 years old, (3) living in the boarding school for at least 6 months, (4) have a good awareness, (5) be able to communicate well, (6) willing to participate in this study. Exclusion criteria was patient who had symptoms of severe mental disorder / relapse.

The inclusion criteria of the general informants were (1) stay in the boarding school, (2) caring and having information about the the rehabilitant, (3) willing to participate. Data were collected through interviews with an interview guide and recorded with an audio recorder. Informed consent was given to the informants to obtain information about the study, the right to participate and confidentiality were guaranteed including anonymity.

Giorgi method was used in data analysis which has 6 stages (Giorgi as cited in Oglesby, 2011): searching for the meaning as a whole, making sense of each unit, transforming each meaning of the unit into a psychological expression, making structures, validating data, and getting a description of the importance by asking back to the informant about the overall meaning of their life experiences.

## **The results**

### **Demographic data**

9 informants consists of 7 main informants and 2 keys with anonymous informants were describe in Table 1.

Table 1 Demographic characteristics of informants

Name	Sex	Age (year)	Education	Duration (year)	Informant
Indah	P	28	SMU	3	Utama
Nuri	P	30	SMU	1	Utama
Sri	P	28	SLTP	4	Utama
Ira	P	51	SLTP	4	Utama
Endah	P	23	SLTP	8	Utama
Wawan	L	30	SMU	3	Utama
Sulaiman	L	29	SMU	1	Utama
Fitri	P	23	SLTP	7	Kunci
Anto	L	25	SLTP	5	Kunci

### **Lived experience**

Spirituality of people with schizophrenia experience at boarding school is described by the nine themes that fit with the research questions. There were 3 main themes:

#### ***Emerge: 1. The meaning of spirituality***

Throughout the years living in the boarding school, the informants developed their own meaning of spirituality. 2 themes of the meaning of spirituality were constructed:

a. Closed to God.

Closed to God was described by informants that they felt that their faith increased, closer to God and humility in spiritual activities as participant expressed:

Lived in boarding school ... my spiritually is growing, closer to God..

(Indah)

... inner peace, more reverent in praying .. feel calm when participating in spiritual activities ...

(Nuri)

b. Increasing religious practiced

The meaning of spirituality was expressed as the increase in religious practiced described by informants such as as praying, read Quran and dzikr. There were some examples of religious activities that they more regularly than before they lived in boarding school.

... never praying when I am sick, now I do more regularly. Never sunah praying, now sunah praying, praying together, read quran ...

(Indah)

...encourages us to more regularly in doing religious practices ... praying, read quran, read surah for healing, Duha prayer, nariyah prayer ...

(Endah)

## **2. The experience of life in boarding school**

a. Studied more about the religion

Living in boarding school can make the rehabilitant studied more about religion such as prayer, how to read quran, how ablution, prayers and abutheaven and hell. Here are some descriptions of the informants:

... here, we know the ways of proper ablution, ... learn about heaven and hell ...

(Endah)

This also confirmed by the key informants that the rehabilitants follows the lecture to study religion science as the following description:

... fasholatan (about praying), daily praying, fikih like pillar of Islam, recitation ( reading Qur'an) , ..

There is a schedule arund one and a half hours until they understand, write themself constantly, read and memorize together, .. repeated up to 1000 times and then tested one by one... Told to repeat, the gift is given if they can repeat...

(Fitri)

b. Improving social relationship

After living in the boarding school, informants describe that social relationships have been increased such as having friend to tell the stories even there is a conflict amongs them. In addition, making friends with fellow students (santri) is also good for them where santri are good people so that they become influenced them become well too. This is expressed by the informants as follows :

... last time never have friends, now get along with each other, many of friends, even there is a conflict ...

(Endah)

Feeling happy ... because a lot of friends and can hang out with the santri as well. Although sometimes sad ... it is better here, because hanging out with normal people... hanging out with santri as a good friend ...

(Wawan)

... having relationship with good friends, with santri, I do not feel inferior. They said that they love. I like to have many friends, how I can tell the story...

(Sukir)

c. Concern in the future (hope)

Concern to the future is described by the rehabilitant such as in family , married as general people, concern when they passed away, hope of living in heaven. Moreover, some of them expected to be able to work, live independently and not depend on others.

It is described by the informant as follows :

... I want to have independent living, independent ... could work, self-sufficiency, any kind of employment. I ever worked as SPG , .. work at Chinese restaurant, ... want to teach kindergarten, but only have a hundred thousand... ever teach at friend's house , teach quran ...

(Endah)

Having family ..., having children, having a wife , as other people, go to work ... because I have a store in my hometown.

(Wawan)

The importance of spirituality for the informant can be disclosed as a provision in their life such as :

Spiritual is important, in the mental hospital .. we pray or not, they do not care.. praying is very important for life, even it is not mandatory for sick person, pray is our god in our life after .. .

(Sukir)

### **3. The impact of spirituality**

a. Recovery from mental illness

Spirituality influence the informants who live in boarding school. It is described that spiritual healing can help decreasing of the symptoms of their mental illness other on taking medication. Also as a creature of God, they sometimes ask for God for healing because they believe that the illness is also from God as expressed by the following informants:

... could help another from non-medical curative due to the prayers can open the mind, not cramped, reduce afraid feeling...

(Nuri)

It also described by caregivers in boarding school that all diseases comes from God, as the following expression:

Spirituality is very important, gusti Allahe is gone , as long as remind the prince, if remembered that diseases from God, God give healing from reading Asmaul Husna ... together is more easier ...

(Anto)

b. Symptoms management

The informant claimed to be able to control their symptoms such as paranoid and anxiety are reduced with spiritual activities and pray to God as expressed by the following informant :

..ever run away ... ,now fell at home , get well , there is no a hallucination, not afraid of people would be killed me. If heard the hallucination even fear, usually at night. Now, I know how to handle it: pray , istigfar so that the ghost is not disturbed me ...

(Sukir)

..religious activities make me happy... remember (Allah ): prayer. If I have headache just praying.. if paranoid I am praying, so that my paranoid become reduced .

(Wahyu)

c. Behavior Change

The impact of spirituality on people who live in boarding school can change the behaviors not only as an increasing in the religious activities but also moral improvement. As revealed by the following informant:

... last time, I wear jeans, wear short shirts, like a lack of faith ... now I wear the hijab , wear clothes ...

(Sri)

The same thing was also described by the caregiver as follows :

...before stay here is not polite, open the leg when sit down in the foolr even there is people around, Alhamdulillah now is not like that.

(Fitri)

d. Changes of emotions

Changes emotions were become more calm are felt by informants who lived in the boarding school as an example of the following informants :

...I am satisfied living here, plus happy ... reduced my angry ...

(Ira)

...First, I have unstable emotions ..., now, I never angry ,

(Sukir)

## **Discussion and limitations of the study**

### ***The meaning of spirituality***

Spiritual is personal, unique experience for each person (Verghese, 2008). Spirituality is concerned by the direct experience with the higher consciousness in a person, the internal space (Polatajko as cited in Smith & Suto , 2012). In this study, informants revealed an increase in faith and feel closer to God. These results are consistent with previous research that spirituality can make closer to external forces (God) (Smih & Suto, 2012).

The meaning of spirituality sometimes overlapping with religion, in which its broadest sense as spirituality (relating to transcendent and address the main question of the meaning of life) and religiosity (specific behavior, social, doctrinal and denominational characteristics). Moreover, religious or spiritual word widely used to refer to activities of daily living (Smih & Suto, 2012). This is consistent with the results of this study that most of the informants reported an increased of religious practices such as praying, read quran, dzikr prior stay at the boarding school.

### ***The lived experience and the impact of spirituality in boarding school***

During staying at the boarding school, peoplewith schizophrenia can learn the science of religion more deeper. This is similar that the religious and spiritual meanings have relevance relationship. Living in the boarding school allows patients to study religion together and having contact with other patients or the students (santri). This is similar to the results from previous studies that spiritual experience can help individuals to improve their social relationships (Eeles, Lowe & Wellman, 2003; Mamani, Tuchman& Duarte, 2010).

Spirituality is also associated with the hope in their life after death and the hope of a good (Huguelet et al, 2007 ). It also can has similar results with previous studies (Utterrainer et al., 2011). Furthermore, hope is one of the domains of the quality of life of individuals with

schizophrenia. This is consistent with results of previous studies (Mamani, Tuchman & Duarte, 2010; Mohr et al., 2011).

In this study most patients express a spirituality influence in their lives such as their emotions are more stable. This is in line with previous study that individuals with high spirituality has a sense of lower "anger " (Labbe & Force, 2010). Spiritual is also reported to be coping for symptom management such as paranoid as most of previous studies (Mohr et al, 2011, Mamani, Tuchman & Duarte, 2010; Rosmarin et al., 2013).

The most important impact is that the spirituality is one factor for the recovery of patients with schizophrenia other than with medication. Spirituality influence the healing for people with schizophrenia which are similar with previous studies (Fallot, 2007; Pergament, 2007).

This study has several limitations such as the key informants who have limited expression or limited exploration about what are their lived experienced since it is as one of the symptoms that people with schizophrenia have poor speech. Although researchers also received additional information from the key informants but the main subject is rehabilitant in order to get their spiritual experiences. In addition, all respondents lived in a same boarding school, where each boarding school may have different facilities. Using the experience of some rehabilitant in different boarding school may provide different results and more accurate findings.

### **Nursing implications**

This study provides an overview of the meaning and the impact of spirituality for people with schizophrenia. The implications for nursing practice and nursing education is that this study can help nurses to understand how the spirituality drive people with schizophrenia. In addition, nurses can use religious or spiritual activities in the nursing practices or provide assistance religious activities in the hospital or in the community. The intervention is not only in the form of lectures but also can be in the form of mentoring /support for the provision of spiritual activities for people with schizophrenia.

### **Conclusions and recommendations**

This study reflects the overview of the lived experience of spirituality in people with schizophrenia who live in boarding school. There are three themes derived from this study: the meaning of spirituality, the experience and the impact of spirituality.

The results of this study recommend that nurses and or mental hospitals should provide facilities for people with schizophrenia for their spiritual growth. In addition, nurses need to provide support for them to maintain their religious activities as usual before hospitalization.

The lived experience in this study was give an overview of schizophrenia people who living in the boarding school (Islam). Therefore, further research can explore the lived experience of spirituality from different of view such as from the family and also the nurses or lived experience with a different religion. In addition, since schizophrenia patients have limitation on their speech as one of their symptoms, further research is needed by using different method in collecting data such as by using focus group discussion (FGD).

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