Illness Perception of Schizophrenia among Schizophrenic Outpatients

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Abstract: Schizophrenia as a chronic illness requires continuous treatment to prevent severe symptoms. The schizophrenic patients must have appropriate coping in order to continuously follow the treatment that determined by the medical team. Cognitive illness representation has a role in determining coping that is chosen to deal with problems. It consists of identity, cause, timeline, consequences, and controllability dimensions. Schizophrenic outpatients in this study had good identity because they labeled their symptoms as a part of schizophrenia. However, majority of them had less perceived on schizophrenia as chronic and cycle illness, negative consequences of schizophrenia, and treatment controlling schizophrenia. Majority of them also had perceived that schizophrenia was caused by several causes. Temptation from AllAh SWT and followed by stress or worry were the most patient's perception as causes of schizophrenia. Overall participant has experienced rehospitalization because of medication non-adherent. Therefore, we conclude that cognitive illness representation may contribute to the behavior of taking medication as a coping strategy in dealing schizophrenia. According to this, the researchers suggest that nurse should examine the schizophrenic patient's cognitive illness representation in order to know their views of schizophrenia, so the nurse can predict the behavior that they will use to overcome the problem.

1 INTRODUCTION

Schizophrenia is a serious psychiatric disorder. It causes disorganized and bizarre thoughts, emotion behavior and perceptions which is manifested by hallucination and delusion (Videbeck, 2011). Individuals suffer schizophrenia while they have psychotic symptom for at least six months continuously, which is not related to health problems or substance abuse, and seriously disrupt social and occupational functioning (O'Brien et al., 2013). The symptoms will get worse if patient doesn't follow treatment to deal schizophrenia. Therefore, the patient has the appropriate coping strategies to overcome problem because of schizophrenia.

Determining coping strategies that will be used by individuals to cope the illness is influenced by the individual's perception of the illness (Tiemensma et al., 2016). Poorer illness perceptions that individual has are associated with increased involvement maladaptive coping (Knowles, Cook, & Tribbick, 2013). Lobban et al. (2004) found that different illness perceptions about schizophrenia including identity, cause, timeline, consequences and controllability dimension lead different behavioral as coping strategies in order cope the problem (Lobban et al., 2004). Those are suitable with framework of Common Sense Model (CSM) that was developed by Leventhal et. al. (1980).

The CSM illustrates how an individual takes action in order to againts the threat of his/ her illness (Kucukarslan, 2016). The framework of CSM showed that individual's behavior as coping that used to overcome the problem of illness related to individual's perception about the illness (Leventhal et al. 1980). The individual's illness perception could be changed anytime.

There is some coping strategies that should be taken by schizophrenic patients to deal schizophrenia. Adherence to medication is main coping for schizophrenic patients in order to manage their symptoms. Nicolino et al. (2011) found that individual perceived about susceptibility of illness, severity of illness, barrier of medication, and benefit of medication can influence medication adherence of schizophrenic patient. Study by Al-Yahya and Fayad (2013) also found that schizophrenic patients did not take their medication

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continously because they had lack insight about thier illness, such as perceived that they have an organic disorder or did not have psychological disorder eventhought they have positive symptoms. So, the wayof individual's perception about their illness influence their coping to deal the illness. A literature review about medication adherence of schizophrenic patients also found that medication adherence was influenced by patient's perception of illness (Novitayani & Suttharangsee, 2012).

Medication adherence causes relaps in which symptom may become severe. Literature review by Emsley et al. (2013) found that high rate of relaps occurs because of non-adherence in taking medication after first period. Schizophrenic patients who did not adhere to medication have risk 8 times experiencing relapse compared to the patients who adhered to medication (Maharani & Hardisal, 2016). Usually, schizophrenic patients should be admitted to psychiatric hospital when they get relapse or have severe symptoms. Based on study by Pratama et al. (2015), 50% of schizophrenic patients in Psychiatric Hospital Aceh who come to polyclinic have relapse and 62,5% of the patients did not adhere to medication.

Based on all above, researchers are interested to identify the illness perception of schizophrenic outpatients who have experienced rehospitalization. The researchers conducted this study in Psychiatric Hospital Aceh.

2 COMMON SENSE MODEL

The Common Sense Model is a framework of the way to provide behavior as coping in dealing with problems due to the illness. Leventhal et al. (1980) developed Common Sense Model (CSM) that consists of illness representation, coping and appraisal. Initially, individual will provide illness representation, cognitive and emotional illness representations, based on information. Those illness representations affect the coping strategies of individuals with purpose to overcome the problem regarding to the illness. Coping strategies will be set up through behavior. Lastly, individuals evaluate their coping if the coping is effective or not in facing the problem because of the illness.

This study identifies cognitive illness representation as part of illness representation. It considered as a lay individual's framework of thoughts or belief about illness. Cognitive illness representation consists of five dimensions including identity, cause, timeline, consequences, and controllability dimensions (Leventhal et al., 1980). Identity refers to statements regarding belief about the illness, label, and knowledge about its symptoms. Cause refers to beliefs regarding the factors that are responsible for causing the illness. Timeline refers to belief about the course of the illness (such as chronic, acute, etc.) and the time scale of the illness symptoms (such as persistence, temporary, etc.). Consequences refer to belief regarding the impact of the illness on quality of life of functional capacity. Controllability refers to belief about the efficacy of treatment and personal coping that may alter the illness.

Cognitive illness representation associated with a danger control process (Leventhal et al., 1980). The danger control process refers to how the individuals perceived the threat of their illness and what they do to overcome the illness.

3 METHODS

This study is descriptive design that conducted in Aceh, Indonesia. The study aims to examine illness perceptions, especially cognitive illness representation, among schizophrenic outpatients who come to the polyclinic in Aceh Psychiatric Hospital. There are some objectives in this study as following:

1. To identify illness perceptions of schizophrenic outpatient on identity dimension
2. To identify illness perception of schizophrenic outpatient on cause dimension
3. To identify illness perception of schizophrenic outpatient on timeline dimension
4. To identify illness perception of schizophrenic outpatient on consequences dimension
5. To identify illness perception of schizophrenic outpatient on controllability dimension

2.1 Inclusion Criteria

Forty participants who participated in this study were schizophrenic outpatients from polyclinic of Aceh Psychiatric Hospital, Indonesia. The inclusion criteria consist of suffering schizophrenia that is diagnosed by the psychiatrists at the Aceh Psychiatric Hospital, aged between 18 to 60 years old, having hospitalization at least twice since diagnosis, scoring of the Brief Psychiatric Rating Scale (BPRS) less than 41, good communication, and willing to participate in this study.

2.2 Instruments

Three instruments were used in this study. There are the Brief Psychiatric Rating Scale (BPRS), the Demographic Data Questionnaire (DDQ), and the Cognitive Illness Representation Questionnaire for Schizophrenia (CIRQS).

2.2.1 The Brief Psychiatric Rating Scale (BPRS)

The BPRS was as screening tool to screen potential patient in this study through assessing both their positive and negative symptoms such as anxiety, depression, hallucinations, suspiciousness, and other unusual behavior. The BPRS was developed by Overall and Gorham (Leucht, et al., 2005). The BPRS has 18 items to assess psychiatric symptoms with Likert scale from 1 (no present) to 7 (extremely severe).

The BPRS divided into seven categories involving normal (score 18), borderline ill (score 19-30), mildly ill (score 31-40), moderately ill (score 41-52), markedly ill (Score 53-64), severely ill (score 65-83), and extremely ill (score 84-126) (Leucht, et al., 2005). In this study, the researcher used BPRS score less that 41 which is consider as normal (score 18), borderline ill (score 19-30) and mildly ill (score 31-40) to recruit participants.

2.2.2 The Demographic Data Questionnaire (DDQ)

The DDQ was developed by researchers with purpose to measure demographic data. It consists of age, gender, education level, occupation, monthly income, number of hospitalization, and length of illness.

2.2.3 The Cognitive Illness Representation Questionnaire for Schizophrenia (CIRQS)

The CIRQS was used to assess cognitive illness representation of mental health problem for schizophrenic patients. The CIRQS was modified from the IPQS that was developed by Lobban, Barrowclough, and Steven (Lobban, Barrowclough, & Jones, 2005). The CIRQS has five dimensions including identity, cause, timeline, consequences, and controllability dimensions. The format of the CIRQS is a combination between dichotomous and the Likert scale.

The identity dimension has several lists of negative and positive symptoms. The item statement of symptoms are scored from 0 to 1 (dichotomous) with yes = 1 and no = 0 for having had symptoms since the mental health problem occurred and scored 1 for each symptom if the subjects gave an answer in the part of mental health problem. Cause, timeline that consists of acute/chronic and cycle sub dimensions, consequences, and controllability dimensions had positive and negative statements (21, 8, 9, and 4) with a 5-point Likert scale.

2.3 Validity and Reliability of The Instruments

The content validity of the instruments were evaluated by three experts including two lectures from the Faculty of Nursing in Prince of Songkla University and a lecture from the Faculty of Nursing in Indonesia University. The researchers revised the instruments based on suggestions from three experts. The CIRQS had a good content validity index (0.89).

The reliability of the CIRSQ, except symptoms, was testes for internal consistency by using Cronbach's alpha coefficient. The CIRSQ was accepted because the reliability value of Conbach's alpha coefficient was 0.81. For the symptoms, one part of the identity dimension of CIRSQ, the reliability was tested to examine inter-rater agreement by using Kappa coefficient and the value was 0.69. The kappa value of 0.69 was in substantial agreement range between the first test and second test (test-retest) (Landis & Koch, 1977 as cited in Sim & Wright, 2005). The symptoms questionnaire was accepted, because the reliability value of the Kappa coefficient was greater than 0.4 (Sim & Wright, 2005).

4 RESULTS

Descriptive statistic, especially frequencies and percentages was used to analyze the data in this study. Score of the BPRS among patients in this study was in range 18 -30. All of the results in this study will be explained more in detail as following.

4.1 Demographic Data

The results showed that majority of participants were male (65%), age in adult category (95%), senior high school (42.5%), and rehospitalization from 2 until 5 times (70%). Mostly participants have length of illness from 11 to 15 years (45%), and occupation (87.5%).

Table 1: Frequency and percentage of the participants by demographic data.

Characteristic	N	%
Age		
Mildly Adult (18 – 25 years old)	2	5
Adult (26 – 65 years old)	28	95
Gender		
Male	26	65
Female	14	35
Educational level		
No formal education	1	2.5
Elementary school	5	12.5
Junior high school	9	22.5
Senior high school	17	42.5
University	6	15
Others	1	2.5
Occupation		
Yes	25	62.5
No	15	37.5
Monthly income (IDR)		
No income	15	37.5
300,000 – 1,000,000	17	42.5
> 1,000,000	8	20
Rehospitalization		
2 – 5 times	28	70
6 – 10 times	8	20
11 – 15 times	4	10
Length of illness		
1 – 5 years	3	7.5
6 – 10 years	7	17.5
11 – 15 years	18	45
16 – 20 years	6	15
21 – 25 years	4	10
31 – 35 years	1	2.5
41 – 45 years	1	2.5

Table 2: Frequency and percentage of the participants by identity level.

Identity level (proportion score)	n	%
Low identity (0 – 0.33)	2	5.0
Moderate identity (0.34 – 0.67)	5	12.5
High identity (0.68 – 1)	33	82.5

Table 3: Frequency and percentage of the participants by cause dimension.

Causes of schizophrenia	n	%
Stress or worry	27	67.50
A gem or virus	4	10.00
Chance or bad luck	11	27.50
Allah SWT	29	72.50
Family problems	23	57.50
Alcohol	6	15.00
My Personality	12	30.00
Death of a loved one	7	17.50
Thinking about things too much	26	65.00
Being bullied by others	15	37.50
Hereditary; it runs in my family	7	17.50
Poor medical care in my past	15	37.50

Causes of schizophrenia	n	%
My own behavior	13	32.50
Money worries	23	57.50
Overwork	8	20.00
Taking illicit drugs	7	17.50
Brain damage or abnormality	8	20.00
Chemical imbalance in the brain	5	12.50
My mental attitude, for example, thinking about life negatively	9	22.50
A trauma; something disturbing or shocking that happened in my life	15	37.50
Black magic	14	35.00

Table 4: Frequency and percentage of the participants by chronic sub-dimension, cycle sub-dimension, consequences dimension, and controllability dimension.

	Categories	n	%
chronic sub-dimension	Strongly perceived	6	15
	Less perceived	30	75
	No perceived	4	10
cycle sub-dimension	Strongly perceived	9	22.5
	Less perceived	25	62.5
	No perceived	6	15
consequences dimension.	Strongly perceived	13	32.5
	Less perceived	25	62.5
	No perceived	2	5
controllability dimension	Strongly perceived	17	42.5
	Less perceived	23	57.5
	No perceived	0	00.0

4.2 Cognitive Illness Representation

4.2.1 Identity Dimension

Most of participants had high identity level (82.5%). High identity has similar meaning with good identity. It means the participants can identify their all symptoms as part of mental illness or schizophrenia.

In this study, majority schizophrenic patients had perceived the symptoms that they experienced were part of the condition as well as schizophrenia. The previous study by Lobban, Barrowclough, & Jones (2004) showed that the symptoms that were suffered by schizophrenic were identified as a mental health problem.

The result of the current study in table 2 could be happen because majority schizophrenic patients had suffered schizophrenia more than five years and rehospitalized to psychiatric hospital, so they were aware and more understand about their symptoms related to mental illness. A qualitative study by Guner (2014) also found that schizophrenic patients can define their symptom and they were aware that they experienced the symptoms as part of schizophrenia.

The gender may influence this result. Ward and Besson (2012) reported that overall patients with mental health problem that all of them are men labeled the symptoms as mental health problem. In this study, majority of participants were men.

While the schizophrenic patients belief that their symptoms is attributed to mental health problem or schizophrenia, they could be decided to take medication as doctor prescribed in order to reduce the symptoms. According to literature by Lobban et al. (2003), patient with mental illness were more likely to take medication adherence while they had labeled that their mental illness as viewed from their symptoms is a mental illness.

4.2.2 Cause Dimension

According to CIRQS, there were 21 causes of schizophrenia. The result showed that majority participants perceived temptation from Allah SWT (72.5%), and stress or worry (67.5%) as causes of their mental health problem, schizophrenia. All of participants had perceived cause of schizophrenia more than one.

The exactly cause of schizophrenia is unknown until now. However, there is some cause that may affect someone suffering schizophrenia (University of Maryland Medical Center [UMMC], 2011). In

this study, each participant had perceived more than one the cause of mental health problem or schizophrenia. In the first rank, participants had perceived temptation or test from Allah SWT as cause of their mental health problem or schizophrenia. It can be happen because of all participants are Muslim. The Islamic view of the disease is a test or temptation given by Allah SWT and if we are patient in facing it, our previous sins will be erased. In Surah Al Baqarah (155), Allah SWT says that we will indeed give you test, with little fear, hunger, lack of wealth, soul and fruits. This is also supported by the words of the prophet Muhammad SAW that a Muslim is struck by an unpleasant, sick or other thing, and Allah SWT will erase his mistakes, and his sin will fall as leaves falls down from the tree (Muttafaq'alaih Hadist). In Islamic psychology, Islam views personality as a unity of body and mind aspects, so individual seek answers to each question through the mind by using their energy and abilities in the physical world in a constructive way and satisfied with the answer they find because it is based on the word of Allah SWT (All of Surah in Al-Qur'an), philosophy and science (Ashy, 1999). Therefore, participants feel confident to belief that Schizophrenia or mental health problem is the will from Allah SWT as a test.

The second rank is stress or worry. Another study by Hussain and colleagues (2017) found that most of schizophrenic patients strongly belief on stress or worry, family problems, lack of friends or people who care me, thinking about thing too much, money worries and lack of sleep as cause of mental health problem. Stress that is experienced by individual in crisis situation in their life is a critical factor in development of brain dysfunction against psychotic susceptibility (Green et al., 2014). Stress increases neurotransmitter of dopamine (Fortinash & Worret, 2004) that causes the appearance of psychotic symptoms which indicate schizophrenia (Videbeck, 2011).

4.2.3 Timeline Dimension

Timeline dimension consist of chronic and cycle sub- dimensions. Based on table 4, the result showed that majority respondents had less perceived of mental health problem or schizophrenia as a chronic illness (75%).

The same result also found in cycle sub-dimension like showed in table 4. Majority respondents had less perceived of mental health problem or schizophrenia as a cycle illness (62.5%).

Based on the results, most of the participants had less perceived that schizophrenia is a chronic and cycle illness. It means the participants belief that schizophrenia would last for short time. Another study also showed the same result that the schizophrenic patients were less belief on schizophrenia as chronic and cycle illness (Wall et al., 2017). Hussain and colleagues (2017) found that general schizophrenic patients were unsure about mental health problem as chronic and cycle illness. Based on study in Turki, even though some schizophrenic patients had perceived schizophrenia as chronic illness, most of the patients did not exactly understand about the course of schizophrenia (Guner, 2014). In most cases, mental illness is viewed as an acute illness that it will occur in particular situation like after individual experiences stressful of their life events (Petrie et al., 2008).

The way of schizophrenic patients' beliefs about the course of schizophrenia will influence their behavior to face the health problem from schizophrenia, such as taking medication. The previous study found that perceiving an illness condition as chronic was significantly associated with medication adherence (Aflakseir, 2013).

4.2.1 Consequences Dimension

The result in table 4 showed that majority participants had less perceived of negative consequences of the mental health problem or schizophrenia (62.5%).

The consequences dimension involves beliefs about negative impact of mental health problem on the individual's personal life, financial, and relationship with others (such as family, social). The participants perceived that mental health problem or schizophrenia had negative consequences in to their life process, however, most of them still had less perceived on negative consequences of its.

Similar result also found in study by Wall and colleagues (2017). In that study, schizophrenic patients adopted that schizophrenia has less negative consequences on physical, social and psychological functioning. Schizophrenic patients in Mexican believed that the schizophrenia affect their life, but the study did not explore more about kind of consequences that changed their life because of their mental health problem (Gomez-de-Regil, 2015). In the other hand, study by Hussain et al. (2017) is not only reported schizophrenic patients' beliefs about negative consequences because of mental health problem, but also defined in detail kind of consequences that they experienced (such as

their daily activity, money, and relationship) based on the contain of the questionnaire used in that study.

In the present study, some participants had no income because they did not have occupation (37.5%). The rest of participants had occupation; however, their income is insufficient to meet their own needs (table 1). Thus, the data of monthly income in table 1 supported the negative consequences on financial problem in consequences dimension (statement no. 1 "I do not have any job because of my mental health problems" and statement no. 3 "My mental health problems have financial consequences for me").

The severe symptoms make schizophrenic patients difficult to maintain their function and relationship with other as negative consequences (Nicolino et al., 2011). Therefore, we can conclude that schizophrenic patient's perception about consequences focus on the patient's condition when the patient has severe symptoms.

4.2.1 Controllability Dimension

According to table 4, there were slightly different percentage perception of schizophrenic patients between less perceived and strongly perceived on the effectiveness of treatment in order to manage the symptoms of mental health problem. The result showed that 57.5% of participants had less perceive of positive perception about controllability followed by strongly perceived (42.5%).

Controllability dimension explores patients' beliefs about how medication controlling the symptoms and preventing negative consequences that figures in the questionnaire. Generally, schizophrenic patients consider that the treatment is helpful to their illness (Gomez-de-Regil, 2015). However, schizophrenic patients were unsure about if treatment can overcome the mental health problems (Hussain et al., 2017). Other study reported that schizophrenic patient's perception about the efficacy of treatment was having some control on their schizophrenic symptoms (Lobban, et al., 2004).

While schizophrenic patients had strongly perceived on the efficacy of medication in managing symptoms of schizophrenia, the patients will adhere to medication and follow rehabilitation program as continuously based on team medical prescribed (Petrie, et al., 2008). So, it is important to schizophrenic patients strongly believe on efficacy of treatment in controlling their severe symptoms to be stable condition. Other than that, the patients should be able to control the side effects from the medication that they take. Therefore, they will continuously take medication as prescribed.

5 CONCLUSIONS

Coping strategy that individual's used has influenced by individual's illness perception, specifically cognitive illness representation. In this study, overall all of participants had experienced rehospitalization more than two times because they did not take medication as prescribe. This may be influenced by their illness perception about schizophrenia. Most participants had less perceived that the treatment could not manage the symptoms so that they did not take medication regularly as prescribed. Moreover, most participants also had less perceived on negative consequences in their personal life, financial, and relationship with other caused by schizophrenia. So, they may feel that it is not important to treat schizophrenia through taking medication continuously. Then, most participants had less perceived on schizophrenia as a long-term illness, so they may take medication only when they experience symptoms or the symptoms getting worse. Furthermore, they also had perceived that schizophrenia is caused by multiple factors and almost all of them able to identify the symptoms as a part of schizophrenia. Therefore, it is important to examine patient's illness perception in order to predict their coping that they used to face the illness. If their illness perception has gaps, misperception or confusion with the concept of schizophrenia, their coping will not suitable to overcome the problem of schizophenia. In this situation, the nurse can provide intervention that can change the patient's illness perception in accordance with the concept of schizophrenia.

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