

The Compliance with Rehabilitation for People with Schizophrenia among Primary Caregivers in Nam Dinh Province, Vietnam

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Abstract

OBJECTIVES: Individuals with schizophrenia manifest the different expressions, behaviors and personality. Failure to comply with rehabilitation for the patient may impair the patient and caregiver's quality of life; preventing the patient from self-care, and it is an economic burden for the family and society and chronic progression of the disease. This study aims to determine the compliance with rehabilitation for people with schizophrenia among primary caregivers.

MATERIALS AND METHODS: Participants of 352 primary caregivers of people with schizophrenia were recruited from Nam Dinh General Hospital and Nam Dinh Psychiatric Hospital, Nam Dinh province, Vietnam. To measure the variable of compliance, the researchers designed a caregiver's compliance with rehabilitation questionnaire. The instrument was validated by three content experts including, a psychiatric physician, a psychiatric nurse and a psychiatric instructor.

RESULT: The research results indicated that the caregivers of people with schizophrenia complied with rehabilitation at a good level of 27.6%, average level of 34.4% and poor level of 38%. There was correlation between caregiver's age, being supported from others and patient's illness severity level and compliance with rehabilitation of primary caregivers of people with schizophrenia.

CONCLUSION: Health-care workers should design an intervention program to improve primary caregiver adherence to rehabilitation for schizophrenic individuals to enhance caregiver's compliance for schizophrenia rehabilitation, which should have relation to caregiver's age, being supported from others and patient's illness severity level.

Keywords: caregivers, schizophrenia people, compliance with rehabilitation, Vietnam.

The World Health Organization has affirmed that mental health is an important component of global health. Mental health problems are believed to be the cause of many serious diseases and disabilities around the world.¹ It is estimated that about 26 million people worldwide suffer from schizophrenia, accounting for 0.7% to 1% of the population.² In Vietnam, according to the 2012 clinical epidemiological survey, people with schizophrenia accounted for 0.47% of the population.³ Individuals with schizophrenia manifest different expressions, behaviors and personality. They are often unaware of their disability and abnormality. The patient's ability to perform daily activities and work is reduced. Mental abnormalities can come on suddenly or slowly after months. The people sometimes also had normal manifestations before the disease.^{4,5} The people with schizophrenia were the most stigmatized and vulnerable of all the diseases that were cared for by the health care profession. To ensure human rights, eliminate stigma and discrimination against individuals with schizophrenia and the effectiveness of community-based care for the people, they are encouraged to rehabilitate at home.⁶ However, non-compliance is a common problem in schizophrenic rehabilitation. The reason was that the patient did not cooperate in the rehabilitation process, inconfidence in treatment at home and lack of support from caregivers.⁷⁻⁸

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Rehabilitation for people with schizophrenia is a major challenge for primary caregivers. People with schizophrenia have difficulty or lack of self-help, communication, and socialization skills, therefore, while having rehabilitation at home, the primary caregivers played an important role to support those.⁹ The caregivers directly involved in the planning and implementation of care and rehabilitation plans for people with schizophrenia. The caregiver of schizophrenic people rehabilitated the patient with medication use, nutrition, hygiene, detection of early abnormal signs and preventing recurrence or progression of acute stage, especially psychological supports.¹⁰⁻¹¹ To affirm the role of primary caregivers in treating and caring for the individuals, the World Federation for Mental Health Federation (2014) has raised the topic of living with schizophrenia.¹² However, by the characteristics of schizophrenia, the caregivers must spend a numerous time taking care and supporting people with schizophrenia adjust to everyday life, leading to the fact that only attention was paid to drug use for the people, but rehabilitation was neglected. Making the patient had lower quality of life, self-care ability, high economic burden on the family and society, and progressively chronic disease.¹³⁻¹⁵ Besides, misconceptions, negative perceptions, caregivers' attitudes about schizophrenia created barriers in compliance with rehabilitation for the people.^{10,16-17}

From literature review, research results indicated that there were various factors associated with caregiver's schizophrenic rehabilitation compliance. Characteristics of schizophrenia people and caregivers such as age, sex, educational level, duration of care, severity of schizophrenia symptom.^{16,18-19} Additionally, some research demonstrated that support from others, access to schizophrenia care guidelines related to caregivers' health and coping styles, which had a direct or an indirect impact on caregiver's schizophrenic rehabilitation compliance.²⁰ However, within this research scope, the researcher focused on age, duration of care, support from others, patient's illness severity level and access to schizophrenia care guidelines, the factors believed to be the most relevant to caregiver's schizophrenic rehabilitation compliance.^{16,18-20}

In Vietnam, before 1998, individuals with schizophrenia were often treated in hospitals, causing hospital overload, the effectiveness of psychological treatment and functional rehabilitation for them was not high. Since 1999, people with schizophrenia received community-based treatment with outpatient care and management.³ Nam Dinh is one of the provinces with a high rate of schizophrenia. According to data reported in 2017, there were 4235 individuals with schizophrenia receiving outpatient treatment in Nam Dinh province. Rehabilitation and management of the patient at home presents multiple challenges; the rate of recurrent schizophrenia in the first 2 years of the disease was about 40%.²¹

The lack of emphasis on application of Dorothea Orem's doctrine of encouraging self-care guidance was also one reason that primary caregiver compliance with rehabilitation was hindered. In addition, Ajzer pointed out a significant relationship

between attitudes, beliefs and individual characteristics for choosing an action, implementing that action through behavioral theory.²² Understanding these factors may affect the decision to comply with rehabilitation of primary caregivers of people with schizophrenia. Therefore, the research was conducted to determine the compliance with rehabilitation for outpatient schizophrenia among primary caregivers.

Materials and Methods

A descriptive cross-sectional and correlational design was used to examine the compliance and the related factors among Vietnamese caregivers of people with schizophrenia in Nam Dinh province, Vietnam. The target population was the caregivers who accompanied people with schizophrenia to the Nam Dinh General Hospital and Nam Dinh Psychiatric Hospital in Nam Dinh province for follow-up visits. The minimum sample size of 300 participants was determined using the G*Power 3.1.9.2.^{23,24} About fifteen percent of participants were added in case of data missing, therefore, the sample size of the study was 352 participants. The convenience sampling technique was used to recruit the sample from these following selection criteria including:

1. Be the primary caregiver of people with schizophrenia
2. Age >18 years
3. Be able to communicate in Vietnamese language
4. Provide care for the individuals at least 6 months prior to data collection and living in the same house.

The demographic questionnaire was developed by the researcher and there were two sections of information about the people with schizophrenia and the caregivers. It contains items of the schizophrenic and caregiver's characteristics. The caregiver's compliance with rehabilitation questionnaire was developed by the researchers. This questionnaire had 28 items, each item score ranged from 1-3 (1 = never or rarely practice, 2 = sometimes, 3 = frequently or always). The total score was calculated from items, the higher scores indicated that the better caregiver's compliance with rehabilitation. The instrument demonstrated a good reliability value as 0.87.

The caregiver's compliance with rehabilitation questionnaire was validated by 3 content experts including, a psychiatric physician, a psychiatric nurse and a psychiatric instructor. The experts were asked to evaluate individual contents on the questionnaire as well as the entire questionnaire. An evaluation was whether individual contents were relevant and appropriate in terms of the construct. The researcher and the major advisor then revised content and others in the questionnaire following the experts' comments and suggestions.

Data were analyzed by using a statistical software computer program. Descriptive statistics were used to describe characteristics of the primary caregivers and people with schizophrenia, and the caregiver's compliance with rehabilitation for the schizophrenia. Statistical significance level was set at $p < 0.05$. Pearson correlation coefficients were used to examine relationships between caregiver's age, duration of

care, being supported from others, access to schizophrenia care guidelines and patient's illness severity level and compliance with rehabilitation of primary caregivers of people with schizophrenia.

Results

The results indicated that most of the primary caregivers were female (77.84%) and married (91.38). The mean age of caregivers was 56.75 years old and they provided care to people with schizophrenia for about 7 years. Almost all of the caregivers were family members who lived with patient with schizophrenia. Two thirds of them were not supported by others in providing care for people with schizophrenia and

were without access to schizophrenia care guidelines. Caregivers with an average family monthly income of 1 to 3 million VND (50 to 130 USD) accounted for the highest proportion of participants (39.8%). The results showed that most caregivers had high school qualifications (42.15%), and caregivers with primary education accounted for 26.15% of participants.

The average age of individuals with schizophrenia was 67.74 years (SD = 12.23) and ranged from 55 to 83 years. The average years of being diagnosed by a physician as having schizophrenia was 7.60 (SD = 5.27) and ranged from 1 to 14 years. Half of the caregivers perceived their schizophrenia severity as moderate. Details are presented in Table 1.

Table 1: Frequency, mean, standard deviation and range of the sample characteristics (n = 325)

Characteristics	n (%)
Caregivers	
Age (years); Mean ± SD, (Range)	56.75 ± 27.05, (23-60)
Duration of care (years) Mean ± SD, (Range)	7.43 ± 2.13, (4-12)
Being supported by others	
Yes	116 (35.69)
No	209 (64.31)
Access to schizophrenia care guidelines	
Yes	137 (42.15)
No	188 (57.85)
Relationship with the individual with schizophrenia	
Spouse	282 (86.76)
Son/daughter	36 (11.10)
Relatives/others	7 (2.14)
Gender	
Female	253 (77.84)
Male	72 (22.16)
Marital status	
Married	297 (91.38)
Single	28 (8.62)
Divorced	0
Widowed	0
Education	
Primary school or lower	85 (26.15)
Secondary school	52 (16.00)
High school	137 (42.15)
Diploma	45 (13.85)
University or above	23 (7.08)
Occupation	
Officers	33 (10.15)
Farmers	115 (35.38)
Industrial workers	84 (25.85)
House wife	71 (21.85)
Others (business, i.e...)	22 (6.77)
People with schizophrenia	
Age (years); Mean ± SD, (Range)	67.74 ± 12.23, (55 – 83)
Gender	
Male	196 (60.31)
Female	129 (39.69)
Duration since diagnosed (years); Mean±SD, (Range)	7.60 ± 5.27, (1 – 14)
Illness severity	
Severe	113 (34.77)
Moderate	182 (56.00)
Mild	30 (9.23)

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The results indicated that the percentage of primary caregivers who never or rarely implemented rehabilitation of self-care skills for people with schizophrenia was a high proportion. The caregivers who never or rarely provided hygiene skills rehabilitation for the individuals accounted for the highest percentage of 50.6%. The people with schizophrenia frequently carried out dressing skills rehabilitation by their caregivers with the highest proportion of 40.1%. The average rate of primary caregivers providing community integration training for people with schizophrenia was a high proportion, in which, 43.5% of caregivers rehabilitated showing an affection ability for people with schizophrenia. However, the highest percentage of caregivers (48%) reported that they rarely

rehabilitated the motor skills for the schizophrenia. The results showed that a high percentage of primary caregivers who never performed training on daily labor for people with schizophrenia. Training labor skills for people with schizophrenia were rarely conducted by caregivers accounting for the highest percentage (56%), sometimes training (23.8%), and frequently training (20.2%). See Table 2.

The results showed that there were relationships between caregiver's age, being supported by others and the people with schizophrenia illness severity level and rehabilitation compliance among caregivers of people with schizophrenia ($r = 0.24$, $r = 0.18$, $r = -0.12$, $p < 0.05$, respectively) Table 3.

Table 2: Compliance with schizophrenic patient rehabilitation of the caregivers

Contents of rehabilitation	Never or rarely rehabilitation	Sometimes rehabilitation	Frequently or always rehabilitation
Rehabilitation of self-care			
1. Eating skills	135 (38.4)	142 (40.3)	75 (21.3)
2. Hygiene skills	178 (50.6)	91 (25.8)	83 (23.6)
3. Dressing skills	73 (20.7)	138 (39.2)	141 (40.1)
Rehabilitation of community integration			
4. Communication skills	68 (19.3)	145 (41.2)	139 (39.5)
5. Motor skills	169 (48.0)	123 (35.0)	60 (17.0)
6. Showing affection	32 (9.1)	167 (47.4)	153 (43.5)
Rehabilitation of labor			
7. Encourage people with schizophrenia to work	170 (48.3)	118 (33.5)	64 (18.2)
8. Training labor skills for people with schizophrenia	197 (56.0)	84 (23.8)	71 (20.2)
9. Assign work with supervision and inspection	183 (52.0)	81 (23.0)	88 (25.0)

Table 3: Factors related to rehabilitation compliance among caregivers of people with schizophrenia

Factors	Compliance (r)	p
Caregiver's age	0.24	< 0.05
Duration of care	0.34	> 0.05
Being supported by others	0.18	< 0.05
Access to schizophrenia care guidelines	0.52	> 0.05
Patient's illness severity level	-0.12	< 0.05

parenting, and that the caregivers faced challenges in living with people with schizophrenia.^{10,13,16} Part of the reason was that people with schizophrenia were unable to work and needed regular caregivers, leading to an economic burden on their family. Thereby, it can be seen that the compliance with rehabilitation for people with schizophrenia is very necessary and important. When performing rehabilitation for people with schizophrenia, they can participate in working activities, then it creates a better economy and happiness for the individuals and reduces the economic burden on their family.

Discussion

The research results revealed that the proportion of the female caregivers was 77.84 %, which was higher than the male caregivers. Most caregivers of people with schizophrenia were relatives and lived with them. The results were similar with a previous study of cases where people with schizophrenia lived with the caregivers in a separated area or were locked up for reasons of schizophrenia characteristics.²⁶ The isolated life of the people presented a challenge in the compliance with rehabilitation of the caregivers for the individuals. Moreover, the average monthly income of families with schizophrenia was low, which placed the families in difficult circumstances. These findings were congruent with previous studies that mental status, self-efficacy and parenting stress affected

The education level of the caregivers below high school accounted for a high percentage (52.3%). This made it difficult to provide knowledge about schizophrenia and rehabilitation methods for caregivers to employ. Moreover, in Vietnam, the availability of health education programs for people with schizophrenia and their caregivers is quite limited.^{9,10} Due to limited understanding, some caregivers believed that schizophrenia was caused by ghosts, therefore, instead of complying with treatment and rehabilitation, the caregivers worshipped and tried to exorcise the evil, often making the impact of the disease to worsen.^{6,27} This was a contributing factor to the challenges the caregivers faced in complying with rehabilitation for people with schizophrenia. The results were similar with previous studies related to caregivers' characteristics displayed by people with schizophrenia.²⁸

Compliance with rehabilitation of caregivers for people with schizophrenia

The research results indicated that a high percentage of caregivers did not comply with rehabilitation procedures for people with schizophrenia. Specifically, about half of all caregivers never or rarely provided rehabilitation of hygiene skills to people with schizophrenia. Similar results were found in other studies showing that caregivers presented low compliance with rehabilitation for individuals with schizophrenia.^{8-9,16-17} People with schizophrenia often had mental disorders and were often lazy in regards to personal hygiene, therefore, the caregiver must remind and encourage them to be mindful of their hygiene from the smallest activities such as brushing teeth, washing hair, so the individual with schizophrenia may quickly integrate, reducing the burden on the family. The reason may be that the individuals with schizophrenia were unable to perform complete daily activities; on the other hand, in the process of guiding the patient to perform rehabilitation, when the patient was uncooperative made the caregivers felt stressed and uncomfortable. Therefore, the caregivers may form an overly critical mentality, argue, punish, or shun people with schizophrenia. During rehabilitation of a patient, the caregivers should be trained to be empathetic of the unusual behaviors displayed by people with schizophrenia.⁸⁻⁹ The caregivers should encourage, motivate, and praise people with schizophrenia for rehabilitation compliance; therefore, the patient may make a decision on how to properly implement a certain practice.

Compliance with rehabilitation of the primary caregivers for the people with schizophrenia on community integration achieved moderate level, in which about 48% of caregivers never or rarely provided rehabilitation of motor skills to people with schizophrenia. The process of community reintegration creates opportunities for people with schizophrenia to achieve optimal goals of communication function, psycho-socialism, and occupation. The research results indicated that the primary caregivers implemented to train the patient in communication and loving skills through talking and listening to the patient. However, the instruction of motor skills for the patient was not considered important. Failure to comply with physical activities will not improve the health, fitness, and dexterity and flexibility of the patient.^{10-11,15}

Compliance with rehabilitation of the caregivers for people with schizophrenia on labor was at a poor level, in which, all areas of encouragement for people with schizophrenia to work, training labor skills and assignment of work with supervision and inspection, about half of the caregivers never or rarely implemented these for people with schizophrenia. The reason was training people with schizophrenia on labor took a long time, sometimes the results were not as expected, causing the caregivers to feel depressed and to not want to continue working. Instead of guiding the patient to do things for themselves, the caregivers should work together with the individuals. It is necessary for the caregivers to understand the importance of guiding the work of people with schizophrenia,

not only to improve their family economy, but also as a treatment method to help their disease to progress better.^{8,11,16}

Factors related to rehabilitation compliance of caregivers for people with schizophrenia

The research results showed that there were correlations between age groups, being supported by others and the schizophrenia severity level and rehabilitation compliance of caregivers. The previous studies conducted demonstrated that there were relationships between age group, being supported by others, illness severity level and compliance of caregivers.^{10-11,16,19} Thereby, the researcher realized that the primary caregiver who had free time and experience in care may be able to better implement rehabilitation compliance for individuals with schizophrenia. This result reflected the role of behavioral theory in rehabilitation of caregivers for people with schizophrenia that caregivers with favorable personal characteristics of high education and economic conditions presented better compliance with rehabilitation for people with schizophrenia.²⁰ Therefore, in order to help caregivers to comply with rehabilitation for people with schizophrenia, healthcare providers should provide knowledge about schizophrenia to increase awareness and to help improve the attitude of the caregivers, then, the caregivers may implement better compliance with rehabilitation for the patient.^{8,11} In turn, the compliance to help the patient to improve self-care, labor participation, community integration, will also help to reduce the burden on the caregiver and will help to create favorable conditions for the caregivers in providing care for people with schizophrenia.

Conclusion

Results of this study contributed to the body of knowledge of clinical practice, education and research in nursing. The implication for practice and education should be considered as it was related to the variables influencing caregiver rehabilitation compliance. Therefore, healthcare providers should be sensitive to the presence and absence of these factors that may challenge caregivers at the risk of non-compliance in the rehabilitation of people with schizophrenia. The research results suggested that healthcare providers should provide strategies to strengthen the rehabilitation compliance of caregivers to focus on caregivers' rehabilitation weaknesses for people with schizophrenia including personal hygiene skills, motor skills, and all areas of rehabilitation of labor. The present study provided a baseline data for further study on an intervention of rehabilitation compliance among caregivers of individuals with schizophrenia in Vietnam.

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Conflict of Interest

The authors declare that they have no conflict of interest.

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