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The Phenomenon of Family Empowerment in Caring for People with Mental Disorders

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Abstract

BACKGROUND: Families, especially parents, are the closest people expected to care for people with mental disorders and this means family-focused care mental disorders is the main concept for the management of the illness due to the close relationship.

AIM: The study was, therefore, conducted to explore the phenomenon of applying family empowerment in people with mental disorders as a means of developing instruments.

METHODS: The research was qualitative with a phenomenological approach and data were collected through in-depth interviews and analyzed with the Colaizzi method. The participants include 14 families having someone with mental disorders and selected using the purposive sampling technique.

RESULTS: The results, however, produced seven themes which are the perception of mental disorders, motivation to care, family participation, withdrawal from drugs, spirituality, costs, and alternative treatments.

CONCLUSIONS: This task was found to be the main effort by a family to provide appropriate assistance in accordance with the observed health problems and internal family resources considered capable of deciding are expected to determine the right action to overcome the problems.

Introduction

The basic health research conducted by the Ministry of the Republic of Indonesia showed the prevalence of ODGJ including schizophrenia or psychosis in the households of the province of North Sumatra has increased from 0.09% in 2013 to 0.6% in 2018 and the mental-emotional disorders in the population aged 15 years and above had the highest results in the province of Central Sulawesi with 19.8% and lowest in Jambi with 3.6% while North Sumatra province ranked tenth with 12% out of all provinces in Indonesia [1].

This rate is expected to increase annually unless there are comprehensive mental health management efforts through activities initiated to create an optimal mental health degree for each individual, family, and community with a promotive, preventive, curative, and rehabilitative approach which are integrated and conducted comprehensively and continuously.

The mental health service pyramid established by the Directorate of Health Services also describes mental health services to be continuous starting from the community to the hospital and vice versa. In this case, the community examined is the family environment and this is due to the closeness and availability of families, especially parents, in providing care for ODGJ. This further makes family-focused very important to the management of the illness. Therefore, the placement of family as partners has the ability to improve the quality of life through the provision of required resources, finding the solution to problems, and using appropriate resources to meet health needs [2].

There are, however, very limited studies on the use of family empowerment to care for ODGJ, and those observed only explored the application of the concept to the provision of care for physically ill family members.

The empowerment approach to health services has been applied with several assumptions such as the provision of a good impact on patients due to more control on the health status and the ability of the patient to decide the best option for improvement with the support of health workers.

The research interviews conducted with mental health workers at the Sunggal Puskesmas showed 43 cases of mental disorders were recorded in the

work area of the Medan Sunggal Puskesmas in early 2019 in comparison with the 31 cases in the previous year with a population of 25,760. Further information also indicated family is less motivated and less active in caring for ODGJ patients because they think the problems are permanent and cannot be solved by them. Moreover, this belief is further reinforced by the lack of appropriate knowledge of mental health, as well as the absence of role models, motivators, and health facilities. Therefore, there is a need to equip families with an empowerment model to enable them to play an active role in providing care and consequently improve the quality of life for ODGJ.

Methods

Study design

The research was conducted a qualitative design using the phenomenological approach.

Population, samples, and sampling

In this study, participants used were 14 families with some members having mental disorders and which were selected using purposive sampling.

Instruments

The researchers were the main instruments used in this study, others include tape recorders, field notes, and interview guides developed by researchers based on structured interviews that explored the views and opinions of participants The interview time was 40–60 min and meetings were held twice. The first meeting aimed to foster mutual trust, explain study objectives, sign informed consent, and carry out interviews. Meanwhile, the second meeting was to clarify the results of the first interview and re-ask some unanswered questions. Member checking qualitative study was used to ascertain if the results matched those felt by participants to ensure that the themes identified were accurate.

Data analysis

Data analysis were carried out using Colaizzi technique [3]. Credibility, confirmability, dependability, and transferability were used to ensure data validity. Data analysis were carried out using Colaizzi technique consisting of seven steps which include (1) making verbatim transcript through data evaluation by listening to recorded conversations said by the participants. (2) determination of the significant statements in which the researchers read the transcript data repeatedly 4–5 times, and underlining the important statements of the participants. (3) Classification of significant statements and its collection in a larger unit of data (4) Checking the transcribed data several times (5) classification of existing data into a category (6) Identifying the themes of which the categories already existed and grouping them into potential themes (7) Reconfirming with the participants if the themes were related to their experiences.

Ethical consideration

This research is a talenta research for a doctoral dissertation scheme funded by the University of North Sumatra based on a Letter of Agreement/ Contract Number: 417/UN5.2.3.1/PPM/SPP-TALENTA USU/2020.

Results

The results obtained through Collaizi's analysis showed seven themes which include the perception of mental disorders, motivation to care, family participation, withdrawal from drugs, spirituality, costs, and alternative medicine.

Themes 1. Family knowledge and perceptions of mental disorders

The respondents expressed their lack of understanding of mental health and disagreed with the use of mental disorders for their family members. This was observed from the responses provided such as "Don't understand, because you have never lived with problems like this". (P1)

"It's already addictive, the doctor prescribes the wrong thing". The medicine the doctor gave was drugs, right? (P2)

Other respondents also responded that:

"Oh, I don't know. He said his descendants, his mother's family were like that (P8)".

Theme 2. Family's motivation to provide care

A respondent was quoted to have said that:

"I don't really know because I am lazy to assist during the treatment process and that is why he has been going alone from the beginning of our marriage up to the present moment". (P8).

Theme 3. Family participation in providing care

The respondents reported their family was not invited to cooperate in the caring process.

"My husband didn't want to take care of me, there was no response from him and this made me angry". (P5)

"My mother is not also healthy and old and nothing is expected from the others". (P6)

"The others are avoiding me" (P7).

Theme 4. Withdrawal

The ODGJ were reported by the respondents to have relapsed when drug withdrawal and administration were not prescribed according to the following expression:

"The problem often recurs when they are not given medicine". "The doctor prescribes the medicine should be given twice a day but we only give it once a day". (P1)

"Told to control but never once controlled and now never again". (P4)

"I no longer want to take the medicine like in the past, for example, when I got back home from the mental hospital in the past, I usually find a cure consisting of two yolks and white and I would drink it. now I don't even know anymore" (P5).

Theme 5. Family spirituality

"Personally, I think it is all the result of sin because he used to worship idols and doubt God and this finally made God angry. Only God can heal my husband" (P9).

"I do not regret what happened and I am still grateful to God in order to make Him make a way out for my husband" (P12).

Theme 6. Costs of ODGJ treatment

Respondents reported the cost constraints in treating mental disorders as shown in the following expression:

"It was not totally treated but briefly after which the treatment was stopped due to limited funds" (P3)

"I am a widow my income is only 40 thousand and I have a child with three others, making four. I can't afford to pay for BPJS" (P11).

Theme 7. Alternative medicine

Some of the respondents tried alternative medicine as shown in the following responses:

"I took him for other treatments such as massage, diruqyah" (P1).

"Then after that, alternative treatment was also used in the past, he was taken to uztad (P3).

"I was brought to the pastor for a prayer of deliverance, but my husband's heart was not open to God (P9).

Discussion

The results showed the first theme was that the family's perception of mental disorders was not good and this is similar to the reports of [4]. Meanwhile, family perceptions have a significant influence on the support they have the ability to provide in caring for mental disorder patients. A better perception usually leads to the provision of more support at home. A study by [5] showed the positive influence of family knowledge and perceptions about the benefits of support on the treatment and rehabilitation for mental patients. However, family perceptions can also be affected by the poor disposition of people with mental disorders and this is reflected in the rejection, exclusion, or isolation by the community and their families [6].

The inaccurate understanding of some families on the treatment of ODGJ also leads to negative attitudes towards the patients. This is usually based on the assumption that the disease experienced by the patient is permanent and cannot be cured, thereby, causing the neglect and lack of intervention by the family. Moreover, the hallucinations experienced by patients are considered natural due to their condition and almost all the family members believe the patients are only a burden on the family due to their inability to care for themselves [7].

The second theme showed the motivation of the family in providing care. Family is the unit closest to the patient and has been discovered to be the main treatment for mental disorders. It plays a role in determining the type of care needed at home and low motivation was observed to be leading to less participation of the family. This is associated with the significant influence of motivation in the achievement of certain goals by humans. It is, however, possible to increase motivation through the provision of family-focused nursing care without paying attention only to restoring the patient's condition. Moreover, it has been discovered that the ability of families to consistently care for mentally ill individuals enables them to maintain optimal treatment programs [8]. Meanwhile, a high interest in the family is required to be able to optimally care for family members with mental disorders.

Family is the main support system with the ability to provide direct care for any ill-health or illness to patients. The ability of nurses to achieve success depends on the continuity of the treatment at home to avoid relapse or the need for another visit to the hospital. Moreover, the participation of the family in hospital treatments increases its ability to

care for patients at home to prevent the possibility of relapse [9].

Family empowerment is an essential indicator of a family's ability to access and effectively utilize the mental health system to meet their needs. In the family's perspective, their perceived burden of care and loss could be addressed through proper education and massive information dissemination about mental illness, thereby promoting empowerment. Family empowerment helps the family and community in solving the burden, loss, and stigmatizing experiences with mental illness [10].

Families were observed to lack the required knowledge to apply drug administration with some observed not to be paying attention to the intake of medicines by the patient. Some do not understand that the regularity of taking the medication determines the patient's condition. Moreover, others consider the decrease in symptoms as a sign of wellness and that there is no more the need to take the drugs. It was also discovered that some families do not understand how to control hallucinations and feel as long as the patient is not dangerous there is no need to be worried.

The results also showed the theme of family spirituality and this is in line with the findings of [11] that approximately 40% of schizophrenics and their families believe the disease is related to supernatural phenomena. This was also reinforced by [12] that the formation of a negative stigma is related to beliefs and cultures which consider mental disorders to be due to the activities of the evil spirits. Moreover, the interviews conducted in this study showed mental disorders were due to idol worship. This, therefore, indicates the belief that mental disorders are due to the supernatural is quite high in society, and this further causes negative stigma for the patient and their families.

Families are, however, directly affected by the presence of mental disorders as a social unit and the closest support system to patients. Moreover, they also feel the financial burden of the disease while some families and societies believe mental disorders are embarrassing and have a negative impact on the family. The disease has also been stereotyped by society to be caused by the violation of certain prohibitions, witchcraft, curses, and others based on supernatural beliefs and this usually leads to the transfer of the patients to traditional healers or psychics.

Conclusions

The main focus of this study was to determine the main effort by the family to provide appropriate assistance to address the health problems of a member of the family. Moreover, some internal resources considered capable of deciding for the family determine the right action to be implemented towards overcoming such problems. It is recommended for further research to examine what interventions can be done to families to increase family empowerment in assisting family members with mental disorders.

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