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The experience of adolescents having mentally ill parents with *pasung*

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KEYWORDS

Adolescents; Care; Changes of life; Pasung; Phenomenology

Abstract

Objective: Lack of knowledge and powerlessness make family restrains, chains or confines (pasung) the family member with mental illness. This study aimed to explore the experience of adolescents having mentally ill parents with pasung.

Method: To achieve detailed and accurate understandings of adolescents' experiences, this study used a qualitative research design with a phenomenological approach. Purposive sampling was employed to find teenagers aged 12-19 years old who had mentally ill parents with *pasung*. The data were analyzed with Colaizzi's method.

Results: Parents with mental illness, specifically with physical restrain and confinement (pasung) had psychosocial impact on adolescents. Role changes often occur in the family where teenagers should be a breadwinner and caregiver for their parents. The results of this study were described in three themes: 1) changes of life due to have mentally ill parents with pasung; 2) reciprocity as the reason for taking care of the parents; 3) positive meaning of living with mentally ill parents with pasung.

Conclusions: This study concludes that psychosocial treatment for adolescents living with parents with *pasung* should consider the psychological and social impact as a result of taking care of their parents with *pasung*.

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Introduction

Violent behavior such as attacking and threatening behavior is one of the symptoms which most commonly occurs in people with mental illness¹. In Indonesia, families and communities often deal with violent behaviors from a family member suffering from a mental illness with *pasung* (the deprivation of physical, mental and social of a person with binding or confining)^{2,3}. *Pasung* is performed in many ways, such as: tying hands and feet with chains, wood, locking in a particular room at home, small cages, backyard, under the

house on stilts; or chaining under the tree that makes them cannot move anywhere^{4,5}.

Pasung cases in Indonesia were found 14.3% of people suffered from severe mental disorder. The highest incidence of pasung is in Papua Province, 50% of a family member with a severe mental disorder. In West Java Province, pasung cases are around 10.4% of people with mental illness⁶. West Java provincial government website stated that there are 72,000 people with mental disorders and 10,000 people experiencing Pasung⁷.

Pasung can have a negative impact aggravating the symptoms of schizophrenia. People with pasung may have a

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grudge against the family, trauma, low self-esteem, neglected and discarded feeling, despair, depression, aggravating negative symptoms such as silence and social isolation⁸, vulnerable to infectious diseases such as tuberculosis⁹, and lower adherence to medication¹⁰. The impact of *pasung* is not only perceived by the patient with mental disorder, but also by the family, including children as the closest family members as the manifestation of powerlessness¹¹. The impact of *pasung*, felt by children living with a parent with a mental disorder are: feelings of shame¹²; psychological disorders, such as depression, drugs and alcohol abuse, drop out from school¹³; and feelings of isolation from peers¹⁴.

The focus of this research was children who have parents with mental disorders with *pasung*. It was intended for teenagers because at this age children are at the stage of psychosocial development to strive for identity¹⁵. Disturbances in the development of adolescent identity are associated with *borderline personality disorder* that is manifested in the state of stress and depression in adolescents¹⁶. The development of adolescent identity and the ability to adapt to the environment both psychologically and socially are influenced by the family environment and positive parenting^{17,18}. Teens who have parents with mental disorders, specifically with *pasung*, will feel a greater psychosocial impact because at this stage, children have been involved in taking care of parents with dysfunction in terms of both physical due to the deprivation¹⁹ and parental as a breadwinner in the family.

The study related to adolescents who have mentally ill parents with *pasung* has never been done before, so the researchers were interested in conducting this study through phenomenological study to gain a better understanding on how was the experience of adolescents having parents with *pasung*.

Method

This study used qualitative research with phenomenological approach aiming to examine the adolescents having parents with *pasung* because the phenomenon may be perceived differently within different participants. Phenomenological research findings can assist readers to further enrich their understandings of a particular life experience²⁰.

The study was conducted in five districts in West Java Province starting from January 2016 to June 2016. Six participants were selected by using *purposive sampling* technique with the criteria: 1) teens at 12-19 years of age when their parents experience *pasung*; 2) teens who have at least one parent diagnosed with schizophrenia or severe mental disorders, who are or have been *pasung*; 3) having live experience on the *pasung* of their parents; 4) not married yet when the parents are put in *pasung*, and 5) being able to speak Indonesian.

Method of data collection was in-depth interviews where the researcher as the main instrument. The trial of researchers as the main instrument of the study was conducted by interviews or competency test assessed by research supervisors. The data collection process began with the search of the patient with *pasung* data at one referral hospital for mental illness in Indonesia. From the data, there were 79 patients with *pasung* that had been treated in the

hospital, and 27 of them were married. Because the data of the patients were not complete, the researchers directly contacted prospective participants and screened according to the inclusion criteria that have been set. The researchers gave the research explanation to participants and the parents or guardians about the purpose of the research, the research process and their rights. The interview process began when they agreed to participate in the study, which were evidenced by *informed consent* signed by the participants and the guardians.

The researchers used *Colaizzi's* methods to analyze data because it is suitable for the process of data analysis in the study of phenomenology and it has data validations step²⁰. In the data analysis of the fifth participant, there was no new theme which means the data ware saturated. The researchers interviewed the sixth participant to make sure the data saturation. This study received ethics approval from the Faculty of Nursing, Universitas Indonesia.

Results

Participants in this study were six participants of adolescents having mentally ill parents with *pasung*. Participants of this study ranged from 14 to 19 years of age. They had varied level of education, from elementary to high school/vocational school. The way of *pasung* experienced by parents also varied from confinement to being chained and leglocked behind the house. From the data analysis, identified themes are: 1) changes of life due to have mentally ill parents with *pasung*; 2) obedience as the reason for taking care of the parents, and 3) positive meaning of living with mentally ill parents with *pasung*.

Changes of life due to have mentally ill parents with *pasung*

Changes in life due to have mentally ill parents with *pasung* is the themes that describe the changes experienced by teens when live together with parents experiencing *pasung*. These changes include a change in the role, psychology and social aspects.

Adolescents who have parents with *pasung* tended to have a high dependence, so they have to be the caregiver for their parents. This statement was illustrated as follows:

"My father is bathed once in two days. I just follow the instruction... with my grandfather. It is not rough when I was accompanied by the grandfather. After that, I feed, and give drink to my father" (FJ).

The changing role was the children replace the role of parents, or take over the role as a breadwinner. This statement was expressed as follows:

"Since my father locked up, I became a breadwinner in a family, earned a living for my mother and my brother. At that time my younger brother hasn't worked yet, he was still too young, so I needed to have a job" (Dd).

The second category that formed this theme was a change from the psychological aspect as the emotional consequenc-

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