



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

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### KEYWORDS

Adolescents;  
Care;  
Changes of life;  
*Pasung*;  
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### 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 illness<sup>1</sup>. 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)<sup>2,3</sup>. *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<sup>4,5</sup>.

*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 illness<sup>6</sup>. West Java provincial government website stated that there are 72,000 people with mental disorders and 10,000 people experiencing *Pasung*<sup>7</sup>.

*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 isolation<sup>8</sup>, vulnerable to infectious diseases such as tuberculosis<sup>9</sup>, and lower adherence to medication<sup>10</sup>. 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 powerlessness<sup>11</sup>. The impact of *pasung*, felt by children living with a parent with a mental disorder are: feelings of shame<sup>12</sup>; psychological disorders, such as depression, drugs and alcohol abuse, drop out from school<sup>13</sup>; and feelings of isolation from peers<sup>14</sup>.

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 identity<sup>15</sup>. Disturbances in the development of adolescent identity are associated with *borderline personality disorder* that is manifested in the state of stress and depression in adolescents<sup>16</sup>. 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<sup>17,18</sup>. 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 deprivation<sup>19</sup> 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 experience<sup>20</sup>.

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 step<sup>20</sup>. In the data analysis of the fifth participant, there was no new theme which means the data were 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 leg-locked 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-

es, which were felt by the teenagers as a result of the confinement of the parents. Parents who were chained, leg-logged, or caged made teenagers feel the loss of parental figures because they cannot do activities together as a parent and child. Participants expressed feelings of sadness and pity to see his parents locked. This was illustrated in the following statement:

“So sad, I don’t want to see my father in chains, having meal, passing urine at the same place... I cannot stand on it” (Mg).

“I didn’t know how my father put in *pasung* because I was at school. I have seen my father locked in a cage made of bamboo when arrived at home (crying...). I was so sad and scared to approach him. Since then I rarely leave the house because I was embarrassed if my friends asked about him” (El).

Changes in terms of social aspect are also perceived by adolescents as a result of looking after their parents in *pasung*. They stated that they could not play and socialize like their friends. It was disclosed in the statement below:

“Sometimes I was thinking that I wanted to be like the other children. they have a normal parent, when my father locked ... since he was in *pasung*,. I couldn’t play with my friends like the others..., usually right after school, when my friends were playing around and taking an extracurricular activities, I was just at home caring for my father”.

*Pasung* has impact on the teenager’s life as a child because they have to take care of their parents and take over the role as breadwinner. Changes in this role bring psychological impact on their life due to feelings of sadness to see his parents got *pasung*. Furthermore, it has impact on their relationship with peers because they have to spend the time to assist their parents.

### Reciprocity as the reason for taking care of the parents

Participants stated that they were involved in the process of parental care such as bathing, feeding, and meeting the needs of elimination. Participants said that they did not mind and assumed the cares were done as reciprocation and as a liability because their parents took care of them when they were child. They were still grateful that they still have a parent and they can take care of the parents

This statement was illustrated in the following quotation:

“Alhamdulillah, I still have a father, not like the others maybe who had lost their parents. Although I have to take care of him, but I was still grateful because I knew how sad if you don’t have a parents. My father has taken care of me since I was child... so, when I grow older, it’s my turn to take care of him...” (Fl).

“emm... I have no idea, I just feel normal, because I’ve got accustomed to, since the first I have taken care my father when he was at the coma. Well, right from childhood, my parents took care of me, raised me, now, it’s my duty” (Dd).

### Positive meaning of living with mentally ill parents with *pasung*

Over the life and care for mentally ill parents with *pasung*, teenagers did not only reveal the psychosocial effects but also showed the wisdom by having parents who were in *pasung*. Emotional closeness and increased interaction with parents after escaping from *pasung* were expressed as positive impacts felt by children. Teens feel their parents love them after getting off from *pasung*; it is shown by sleeping together, always paying attention, as well as laughing and talking with parents. This experience was illustrated by teenagers in the following statement:

“Well... I am just happy; because he’s just released... I am happy because I can get close with him and often sleep together” (Bd).

“During confined, I couldn’t do anything... now I am able to have conversation with him... laugh together and so on” (Fl).

In addition, teens also expressed that there was increased responsibility and maturity as a result of having parents with *pasung*. A responsibility to be the caregiver or the family breadwinner makes adolescents more mature in thinking. This statement was illustrated as follows:

“I am more mature, in thinking, working for a living, looking for work, because I never think about it before, yah... it made me realize how hard to earn money” (Dd).

Parents in *pasung* condition lead them to have a high level of dependency to meet the daily needs, so these teens must participate to become caregivers, substitute parents for a living, and be responsible for other family members at home. Feeling responsible was expressed by the participants as the positive meaning for having parents in *pasung* because they regard this as a process of maturation and train them to look at the problem more broadly.

### Discussion

This study aimed to explore deeper experiences of adolescents having mentally ill parents with *pasung*. This study identified themes that describe the experiences of adolescents and the meaning of having mentally ill parents with *pasung*.

The experiences felt by adolescents were the changes in every aspect of their life in the form of roles, psychological and social conditions. Generally, in a family, parents are the caregivers for their children, but the role changed in the case of parents with *pasung*. Changes in the role experienced by adolescents were that they should be the caregivers and the breadwinners. They decided to confine and take care of their parents at home because of the financial issues, difficulty to access health service facility, and relapse after coming back from a hospital. Participants of this study stated that tasks performance done include bathing, feeding, and assisting for elimination needs of their parents. These conditions caused the children should take the roles as the caregiver and breadwinner. Although some partici-

pants said the role as breadwinner was taken by the other parents, yet, they still afraid with the economic condition of the family.

The results of the study are consistent with previous studies showing that the economic burden felt by families is greater if it is associated with the decreased of occupational functions of mentally ill parents that hinder them to work and contribute to the fulfillment of the financial needs of the family<sup>21</sup>. In addition, children in developing countries, including in Indonesia, also tend to be more often to be caregivers for the ill parents due to the cost. Adolescents who live in a nuclear family are involved in family care more often than those who live in a large family as support system in large family is bigger<sup>22</sup>. Two participants in this study live with other family members, such as grandparents and grandmothers. However, the adolescents should look after their parents because their grandparents and grandmothers were not able to do that task.

Having parents with mental illness and *pasung* has emotional and social consequences. These may be caused by the change of interaction between adolescents and their parents during *pasung* period. In this study, one of participants revealed that before his father put in the stocks they often slept together and interacted like father and son, but since the parents got *pasung*, they could not have close relationship, as well as sleep, chat and laugh together. These results are consistent with previous studies reflecting that teens feel lonely and miss their parents. Even though they live together, they see their father as a different man<sup>23</sup>. Problems of closeness between children and parents experiencing mental illness with *pasung* can affect the formation of the cognitive and emotional development of the children, which may eventually lead the teens to the difficulties of attachment in adulthood<sup>24</sup>.

The emotional and social consequences resulted from taking care of mentally ill parents with *pasung* are explained as psychological impacts causing teens to be difficult to socialize like other children. The psychological impact is also perceived by children whose parents have a mental disorder without *pasung*. The psychological impacts described in the previous study about experiences of living with a parent with a mental disorder without *pasung* are anxiety, stress, and pressure disturbing children's concentration at school<sup>25</sup> and have lower self-esteem than adolescents who live with parents without mental illness<sup>26</sup>. The *pasung* leads to feeling of guilty, sadness, and thought of the disease of the family members in the future<sup>5</sup>. Another study revealed that the family also experienced physical exhaustion and emotional impact of taking care of a family member in *pasung*<sup>27</sup>.

Some participants also expressed they could not socialize, such as playing and going out with their friends after school because they have to take care of their parents. They also tended to be more silent and did not have many friends at school because they were afraid that their friends would know their parents' condition. Although other participants still joined extracurricular activities and additional lessons out of school hours, they avoided discussing their parents' condition because they feel embarrassed. Participants in previous studies also felt the same impact. Teens who have roles as caregivers at home tend to keep their activities in secret because they think that their tasks are embarrassing and will reveal the inability of their parents<sup>28</sup>. They also

tend to be quiet and inactive in their group because they do not want to attract the attention of his friends<sup>29,30</sup>.

Adolescents in this study revealed the effects of living with parents in *pasung*. However, most of them stated taking care of their parents was as a form of affection, respect and reciprocity towards parents who took care of them since they were a child. It is also described in previous studies that the reason of family members looking after for family members are due to cultural factors in Indonesia, where it is more in the form of collectivist horizontal requiring children to be more respectful on their parents<sup>28</sup>. Another reason influenced by the proximity of a parent-child in the context of the culture in Indonesia is that Indonesian children tend to have closer ties and greater respect towards their parents<sup>31</sup>.

Adolescents living with parents with mental illness, specifically with *pasung* are responsible for replacing their parents' role. Even though almost all participants in this study revealed that they wished to have normal parents like their friends', other participants said that they were still grateful to be able to take care of parents. They considered this issue to grow in maturity, and wisdom. This is consistent with previous research that reveals adolescents replacing the role of parents who are sick at home. They state that taking care of parents is a learning process to gain independence, but sometimes they still want to live like other teenagers who do not need to do many tasks at home<sup>32</sup>.

This research concludes that parents with *pasung* put adolescents to have various changes in every aspect of their life, such as roles, psychology, and social. They believe that taking care of parents is a form of affection, respect and reciprocity towards parents who raised them since they were a child. Teens assume that experience of having mentally ill parents may make them more mature and responsible.

The limitation of this study are participants who were interviewed experiencing their parents got *pasung* several years ago and two of participants didn't live with their parents because after the parents in *pasung*, they lived with the other family. These conditions can affect the richness of the data. However, they still caring for the parents and giving the instrumental support. Future studies may consider to conduct similar research focusing on adolescents who live with mentally ill parents at the same time as the research process.

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## Conflicts of interest

The authors declare no conflicts of interest.

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