

## Teen caregivers living with schizophrenic fathers in West Java

Sarah Kusumah Bakti<sup>1</sup>, Hana Rizmadewi Agustina<sup>2</sup>, Aat Sriati<sup>1</sup>, Suryani<sup>1</sup>, Noreen Asif Shivji<sup>3</sup>

<sup>1</sup>Department of Mental Health Nursing, Faculty of Nursing, Universitas Padjadjaran, Bandung, Indonesia

<sup>2</sup>Department of Fundamental and Pediatric Nursing, Faculty of Nursing, Universitas Padjadjaran, Bandung, Indonesia

<sup>3</sup>School of Medicine, Keele University, Newcastle, United Kingdom

### Article Info

#### Article history:

Received Jan 29, 2024

Revised Jul 15, 2024

Accepted Jul 30, 2024

#### Keywords:

Adolescent  
Experience  
Father  
Qualitative  
Schizophrenia

### ABSTRACT

Adolescents with fathers who have schizophrenia are more likely to experience emotional dysregulation, negative decisions, a failure to form an identity, inconsistency in decision-making, and failure to adapt. This study is aimed to investigate the lived experiences of adolescents who live with a father who has schizophrenia in an urban area of Bandung City, West Java. The qualitative phenomenological approach was used in this study. In-depth interviews were conducted with six adolescent participants, aged 13 to 22, who live in Bandung City with a father diagnosed with schizophrenia. The Colaizzi method was then used to analyze the interview transcripts. Data analysis produced eight major themes: i) dealing with psychosocial problems and moral dilemmas, ii) a lack of closeness between father and children, iii) exposures to violence inside and outside the home, iv) getting the wisdom behind the catastrophe, v) changing roles and responsibilities, vi) a lack of social support, vii) difficulties to share personal issues, and viii) seeking to build a better future. The adolescents still have opportunities to continue building a better future. Improving health promotion and education programs to manage negative emotions and developing Self-Help Groups for adolescents whose fathers have schizophrenia is thus necessary.

This is an open access article under the [CC BY-SA](#) license.



### Corresponding Author:

Hana Rizmadewi Agustina

Department of Fundamental and Pediatric Nursing, Faculty of Nursing, Universitas Padjadjaran

Bandung 40287, Indonesia

Email: hana.rizmadewi@unpad.ac.id

## 1. INTRODUCTION

Adolescent identity development and the ability to adapt to the environment both psychologically and socially will be influenced by the family environment, where adolescents who have fathers with mental disorders will experience the impact of greater psychosocial disorders. This is largely because at this stage the child is already involved in caring for a father who is dysfunctional in his body, both physically and psychologically, resulting in a father's inability to earn a living [1]. One situation regarded an adolescent where the father's condition was made worse because his wife had a mental disorder and had died by suicide and then he experienced business failure resulting in losses. According to Reupert *et al.* [2], parents who experience schizophrenia can pass on the condition to their children. Conditions that can be experienced by children are externalizing behavioral disorders or higher disorders, behavioral disorders, and developmental disorders, as well as emotional and anxious disorders.

LeFrançois [3] explored the impacts of fathers with severe mental illness when caring for children and recruited ten adolescent participants. The results of the study obtained several themes, namely the mental illness experienced by a father has damaged his relationship with his child due to the side effects of drugs, it is difficult to control emotionally, causing many problems in the family, there are memory problems that affect parenting and there is a great fear that they will pass on their illness to their children [3], [4]. Another study

was conducted by Buanasari *et al.* [1] in Depok West Java using a phenomenological approach with purposive sampling on adolescents aged 12-19 years who have parents with mental disorders. Findings only emphasized psychological and social development for adolescents whose parents had mental disorders and did not focus on the role of fathers

Literature review reveals there is paucity of studies related to adolescents living with schizophrenic fathers in Indonesia. Research conducted by Siagian in Bandung City using a phenomenological approach involved six participants only emphasizes the life experiences of adolescents living with mothers with schizophrenia in Bandung City [5]. None of the study explores the experience of adolescents living with fathers with schizophrenia in Bandung City.

According to WHO, there are 24 million people with schizophrenia or 1 in 300 people [6]. There are many negative impacts caused by parents, especially fathers who experience schizophrenia on the lives of their teenage children. Based on the preliminary data as presented, the researchers seek to conduct in-depth research about the description of the life experiences of adolescents who live with fathers with schizophrenia in Bandung City, especially in the Babakan Sari area. It is necessary to do further research to analyze the possibility of mental disorders faced by adolescents and explored determinant factors to baseline interventions to overcome psychosocial problems in adolescents.

## **2. METHOD**

### **2.1. Study design**

This study used a qualitative phenomenology design. This study aimed to assess adolescents with fathers who have schizophrenia. The experience of adolescents with fathers who have schizophrenia was explored by semi-in-depth interview.

### **2.2. Participants**

Babakan Sari is one of the urban villages in Kiaracondong Sub-district, Bandung City, West Java, Indonesia. Kelurahan Babakan Sari is a densely populated area and consists of 19 RW. Based on data from the Bandung City Health Office in 2021, the Babakan Sari Community Health Center is ranked first with the highest number of schizophrenia patients in Bandung City, with 130 people. Researchers collected data from mental health cadres in the Babakan Sari Health Center area, with the results of eight adolescents living with fathers with schizophrenia. However, only six people met the research inclusion criteria, especially the age criteria for research participants aged 10-24 years. The number of participants in qualitative research with statistical methods can estimate the number of heterogeneous samples, which is around 6-12 informants [7], [8].

### **2.3. Data collection**

The data collection process consisted of pre-data collection, interview stage, and termination stage. During data the collection phase, the researcher conducted screening the adolescents who have fathers with schizophrenia to be potential participants. Health cadres acted as gate keepers who identified the eligible participants. Researchers prepared a comfortable and private environment during the interview with a quiet place to avoid noise. The interview process was conducted based on the time and place agreement that had been agreed by the researcher and participants. The interview for each participant lasted approximately 45 to 60 minutes. The researchers met the participants for three times. The first meeting the researchers explained the purpose of the study and the time contract with the participants. The researchers conducted the second meeting for doing the interview processes. Informed consent form and demographic data form following with gentle reminders were sent before of the interview began. During the interview, the conversation between the researcher and the participant was recorded. The last stage was the termination stage, which was validating the transcripts. In this phase, the researcher validated the description of the phenomena experienced by the participants by reading the results of the interview with the participants. Such activities were done before categorizing the validated data and developed final themes and its interpretation.

### **2.4. Data analysis**

The data analysis method used in the research is the Colaizzi method. The researchers also conducted an accurate analysis of the existing data and combined perspectives, raw data, and document analysis. Colaizzi's data analysis method is the only phenomenological analysis that requires validation of results by returning to participants, to ensure that participants' experiences are interpreted correctly [9]. This procedure helps participants to ascertain whether their answers to questions need to be corrected and ensures that the researcher has not misinterpreted the data [10], [11].

## 2.5. Trustworthiness

Data validity testing can be done by member check, by which participants who have been interviewed are asked to read the transcripts that have been made by the researcher and approved by signing the approval on the in-depth interview transcript attestation sheet [12]. Research can be declared valid if it is able to accurately represent the experiences of participants. In achieving data validity, criteria can be used in research by testing credibility, dependability, confirmability, and transferability [13], [14].

## 2.6. Ethical considerations

This research has assured ethical conduct throughout the research process. Prior to the study, all participants were informed of the aims of this study and their personal rights to withdraw from the study anytime. The researcher also briefed the participants on the study benefits, tools used, the research process, including the recorded interviews using a recorder. Participants who were willing to participate in the study signed the informed consent. However, for participants who were less than 18 years old, the researcher asked their mothers or guardians to represent them. The informed consent included the publication of anonymized responses. The confidentiality and anonymity were maintained to protect participants privacy and dignity.

An ethical review board approved the study to ensure the compliance to ethical conduct and law. This study prioritizes ethics to gain insight into Adolescents with fathers who have schizophrenia while protecting subjects' rights and welfare. Ethical approval was granted from the Research Ethics Committee Universitas Padjadjaran Bandung, Indonesia (with ethical number 1124/UN6.KEP/EC/2022).

## 3. RESULTS AND DISCUSSION

### 3.1. Result

The number of participants was six people, consisting of three adolescent girls and three adolescent boys with an age range of 13-22 years. The education level of the participants was almost entirely high school graduates, but there was one participant who was still in junior high school. All participants lived with their nuclear family. The length of time the father suffered from schizophrenia also varied, ranging from 4-29 years. All participants in this study were unmarried. Table 1 is shown in detail the characteristics of the participants.

Table 1. Characteristics of participants

Participant	Age (Year)	Gender	Education	Religion	Illness period (Year)
P1	19	Male	Senior high school	Islam	±12
P2	19	Female	Senior high school	Islam	±16
P3	16	Male	Senior high school	Islam	± 4
P4	22	Male	Senior high school	Islam	±10
P5	16	Female	Senior high school	Islam	±10
P6	13	Female	Junior high school	Islam	±29

### 3.1.1. Theme 1: dealing with psychosocial problems and moral dilemmas

#### - Sub theme: dealing with psychosocial problems and moral dilemmas

Five out of six participants expressed feelings of sadness when they saw their father's behavior. The first participant expressed displeasure when her father threw a tantrum and made her sad. The following is participant 1's statement:

*"I'm not happy about it, especially if I'm already angry, so it's sad to see, especially if my mother is hurt"* (P1)

The second participant also revealed that when his father experienced symptoms of mental illness, he felt very sad. The following is participant 2's statement:

*"Very sad"* (P2)

The third participant cried when he saw his father's condition. The participant also felt sad when his father threw stones at an unknown person's car, damaging the car and making the participant traumatized, afraid and angry. The following is participant 3's statement:

*"Sad. Then, at that time, I also threw a stone at someone's car until it broke and I was simply sad, sad, traumatized, and terrified"* (P3)

The fourth participant felt sad to the point of feeling down when he saw his father and remembered his treatment of the participant. The following is participant 4's statement:

*"I feel, so I remember the past; I prefer to pain, but if I'm left behind" (P4)*

Participants revealed that they never felt happiness from their family and this made them sad. This makes participants sad. The following is the participant 5's statement:

*"I prefer to cry alone in the evenings at times, and I aspire to be like" (P5)*

- Sub theme: feeling angry and disappointed at father's behavior

Four out of six participants expressed feelings of anger and disappointment at their father's behavior. Participants revealed that although their family was complete, they did not feel happy and felt lazy when dealing with their father. Participants also expressed disappointment at being born to their mother and father now, as stated by the participants as follows:

*"...having a parent like that is not a good thing" (P1)*

*"...is sad, but also angry" (P3)*

*"I don't know, I'm too lazy. Anyway, the family is complete, but is correct" (P4)*

*"Why do I have to be born, but I'm not happy? I wonder at times. If I, for example, do not have the right to happiness, it is better not to be born at all" (P5)*

- Sub theme: feeling worried and sorry for father's attitude

Four out of six participants expressed feelings of worry and pity for their father's behavior. Participants were also worried that their father would hurt their mother when the participant was not at home or that their father disappeared without any news and was found in a location quite far from the participant's house. Participants felt sorry for the condition of their father who had a mental disorder, as stated by the participants as follows:

*"Mother is likewise terrified, especially if she sleeps upstairs when her father is yelling; she thinks more when she wants to sleep at night" (P1)*

*"...so, it's like I feel sorry for my father because having such an illness must be terrible for him, and then he can't distinguish between the real and the unreal, so it's like that for me" (P2)*

*"When I encountered tea somewhere else undressing" (P3)*

*"Yes, it's unfortunate that your father is being bullied by others" (P6)*

- Sub theme: feeling afraid to face his father

Four out of six participants expressed feelings of fear when dealing with their father. Participants felt afraid to be able to direct their father because they were worried about making their father angry, as stated by the participants as follows:

*"I told his father, told his father, but if his father grew furious with me, I became terrified" (P1)*

*"If I was afraid because I wasn't used to it, perhaps because of my father's wealth, it frequently relapsed" (P2)*

*"Sad. I was sad, sad, traumatized, and terrified of at the time" (P3)*

*"I hurled a stone at someone's car till it broke. Afraid of thinking about it, which isn't good, afraid of being furious, afraid of yelling" (P3)*

*"They are also the ones who scare us, doing everything" (P5)*

- Sub theme: participants feel like a burden on the family

Three of the six participants revealed that they felt they were a burden to their family. Participants said they were a burden to their families because they felt they could never make their parents proud and when their parents fought because of them, as stated by the participants as follows:

*"Being the first child feels like a burden to me. Father thinks I'm a burden"* (P3)

*"I feel that being an i in this world was meant to be a burden, and I don't have the right to be joyful in that way"* (P5)

*"Then it was my tea that was bad, and we battled, and my tea was like that"* (P6)

- Sub theme: participants feel confused

One in six participants expressed feeling confused when dealing with their father. The participant did not understand why his father could have a mental disorder. The participant was surprised by the condition of his family who were often given trials, as stated by the participants as follows:

*"It's only a little nauseous. Then there's my father, although I'm not sure why he got sick; I'm also perplexed"* (P4)

*"I'm still not sure, and I'm still perplexed. I'm not sure, I used to go to jail as well"* (P4)

- Sub theme: feeling tired

Two of the six participants expressed feeling tired when dealing with their father. The participant also said that the participant and his mother were tired of his father's condition because they felt that they had done everything possible to deal with his father. The participant felt more tired when his father's mental symptoms relapsed for the second time, as stated by the participants as follows:

*"I've been told how many times I'm weary, but I've done a lot of stuff, so it's usual"* (P4)

*"I was born into a family like that; therefore, I want to prove that I can do it, that I can do it, that I can do it, don't underestimate me, and that I'm exhausted too"* (P4)

*"The ritual also exhausts itself"* (P5)

*"I become tired, and sometimes I let it out by self-harming"* (P5)

- Sub theme: feeling uncomfortable at home

Two of the six participants expressed feeling uncomfortable living at home with their families. Participants said they felt uncomfortable living at home because they often scolded them in a loud voice, as stated by the participants as follows:

*"Yes, when I'm on vacation, I'm lazy at home"* (P4)

*"It's not a home for her; she doesn't have a home to return to"* (P5)

- Sub theme: mistaking his father for someone else

Four out of six participants considered their father to be another figure and not a father. Participants said they could not accept their father's condition because they were worried about threats from their father who would kill their mother, as stated by the participants as follows:

*"I haven't embraced it fully because I'm still worried that what my father claimed about killing my mother was true, therefore I'm afraid of me tea"* (P1)

*"Sad, but also patient. This is not typical of my father"* (P3)

*"Until now, I've felt as if I don't have a father"* (P4)

*"My father is a monster"* (P5)

### 3.1.2. A lack of closeness between father and children

Five out of six participants revealed a lack of closeness between father and child. The first participant revealed that he did not care about his father's condition and the most important thing was the mother's condition. The second participant said he was not close to his father. The third participant revealed that he wished he could be close to his father again. The fourth participant said she prefers to hang out with friends rather than with her family at home. The fifth participant said he wished he had a father who could protect him, as stated by the participants as follows:

*"The key point is my father is free" (P1)*

*"Because of that, I got less close to my father" (P2)*

*"Want to be close again, want to talk a lot" (P3)*

*"So, when I had a day off, I wasn't at home either, I was with my friend" (P4)*

*"You also rarely talk to me if everything is normal" (P5)*

### 3.1.3. Exposures to violence inside and outside the home

- Sub theme: getting bullied by family

One of the six participants was revealed to have been a victim of bullying from her family. The fourth participant said he had experienced rejection and bullying from his mother's family who did not accept his father's condition, as stated by the participants as follows:

*"There's also a family who kicked me out. I used to live at my grandmother's house, but if I'm not mistaken, the person who evicted her now lives in the pine complex, and she knows my father is like that" (P4)*

- Sub theme: getting bullied by schoolmates

Two of the six participants revealed that they had been bullied by their schoolmates. The participant once did not want to go to school because of his father's condition. The participant had resigned himself to the treatment of his friends who made fun of his father, as stated by the participants as follows:

*"My friend warned me, "Don't get too close to him, his father is insane"" (P4)*

*"I didn't want to go to school since I was bullied, but what other options did I have? Just do it" (P4)*

*"My father followed me to school, which is why he threw my bag, slapped me, and shoved me" (P6)*

- Sub theme: accepting violent behavior from father

Three of the six participants revealed that they had received violent behavior from their father. Participants and their mothers also revealed that they had been treated with violent behavior from their father and without cause when they were children, which has traumatized them until now, as stated by the participants as follows:

*"I'm afraid of getting kicked" (P1)*

*"They frequently become enraged, enjoy going out, and holler" (P3)*

*"...father to mother, father acted violently and mother remained silent" (P5)*

### 3.1.4. Getting the wisdom behind the catastrophe

- Sub theme: loves his father more

Three out of six participants expressed more love for their father. The participant wished his father a long life because he loved his father very much and felt that his sister and mother did not really care about his father's condition. Participants felt proud of themselves because they could motivate themselves to be able to earn their own living and strengthen the family. The participant also said that his father still gave attention which made the participant grateful and respected his father despite his mental illness, as stated by the participants as follows:

*"I like it because, while my mother and sister are less supportive of my father, as my mother also stated, I enjoy being on my father's side and defending" (P2)*

*"Love Father" (P3)*

*"Yes, I'm terrified of what's wrong, I don't want to lose my father, and I want to remain by my side till i'am is working and I'm married. I don't want to lose both of them, even though they are both extremely wealthy" (P6)*

- Sub theme: father's condition makes him more patient and grateful

Four out of six participants revealed that their father's condition made them more patient and grateful, which made them get closer to Allah and always support their family. All participants in this study were Muslim, as stated by the participants as follows:

*"I have more patience. hehe, I can be more patient, like not getting angry if my father relapses or whatever, and I'm also grateful that even if I have a father who is not perfect, I can still be given a father" (P2)*

*"So, if you have greater patience, you will be better at being appreciative" (P4)*

*"I'm becoming more resigned. I follow fate, ah yes, maybe this is Allah's destiny for me, right?" (P5)*

*"It's fine if you live together, but it's still thanked God when you see other people who are already split, so thank God it's not like this anymore" (P6)*

- Sub theme: become more independent

Two of the six participants revealed that their father's condition made them more independent. The third participant revealed that his father directed the participant to be more independent because his mother was no longer there and the sixth participant said that having a father with mental illness made him more independent, as stated by the participants as follows:

*"Must learn to be independent. You see, there's no mother" (P3)*

*"i must be able to do things on myself; cannot rely on others" (P5)*

### 3.1.5. Changing roles and responsibilities

- Sub theme: being a breadwinner

Two of the six participants revealed that they had become breadwinners for their families. Participants said they were saddened by the condition of their father who could not earn a living, making participants feel troublesome for their father's family and taking lessons from their house being evicted made participants get a job. Participants revealed that their father's condition did not burden him because he was already working and had his own job, as stated by the participants as follows:

*"Work, indeed. So, when my house was evicted, I didn't have a job when I relocated; thankfully, I found one" (P2)*

*"My aim is that I will be able to provide for my family, even if it is a small amount, and that I will be able to improve my parents' financial situation" (P4)*

- Sub theme: feeling responsible to his father

Three of the six participants revealed that they felt responsible for their father. Participants were responsible for taking care of their father's condition and did various ways to persuade their father to take medication. Participants also said they were responsible for protecting their family, as stated by the participants as follows:

*"Perhaps I feel sorry for them since I'm not sure who else would look after them but their children" (P2)*

*"Calmed down, istighfar instructed to be patient. I also refer to my aunt as" (P3)*

*"As a result, as a child, I must defend my father and ignore what others say" (P6)*

- Sub theme: hoping to make my family happy

Two of the six participants hoped to make their families happy. Participants hope to have their own

house and send their parents to Umrah. Participants said that every time they saw the condition of their father who relapsed with his mental illness, it made them sad but they realized that without him, their father had no one to take care of him, as stated by the participants as follows:

*"Then I'd like to accompany my parents on umrah" (P2)*

*"I also want to purchase a cell phone for me, and I already have one for my father" (P2)*

*"I feel, so I recall the past; I enjoy being wounded, but if I'm left behind, who else would I want to be with?" (P4)*

### **3.1.6. A lack of social support**

Based on the results of the analysis, four out of six participants in this study revealed a lack of support. Four out of six participants expressed the need for support from their families, as stated by the participants as follows:

*"I frequently see my mother since I'm scared no one knows what's happening with her" (P1)*

*"For example, my siblings rarely visit me, so I can count them on my fingers" (P2)*

*"Support from my sister" (P3)*

*"Yes, it is sad. Mother's help is required" (P5)*

### **3.1.7. Difficulties to share personal issues**

Five out of six participants revealed that they did not want to share their condition with others. The participant said that no one knew about his father's condition at school and chose not to tell his mother because he felt that his mother's condition was more painful. Participants revealed that they never told their problems to others because participants often felt awkward from being children to being teenagers. Participants revealed that they kept all their problems to themselves and vented by crying, as stated by the participants as follows:

*"You don't know anything at school" (P1)*

*"Even my friends are unaware; for example, if I relapse, "I try to notify my family. The problem is that if it relapses, it shouts right. Never in that manner. is unknown to any of my friends" (P2)*

*"It's cool, I just wanted to say something. Such stories appeal to me" (P3)*

*"Sometimes she tears in the room, makes no sound, is quiet, the lights are turned out, it hurts, and her chest is tight" (P5)*

*"No, but I've never told my parents (P6)*

### **3.1.8. Seeking to build a better future**

All participants said they already had future plans in the field of work. Each participant has different job aspirations, some want to be a soccer player, train attendant, become a chef, and some want to work abroad, as stated by the participants as follows:

*"I want my mother to succeed and for me to succeed with her" (P1)*

*"Maybe I should work more, and I wish to be a train flight attendant" (P2)*

*"I'm aspiring to be a police officer" (P3)*

*"I'm still waiting, but if I pass and am approved, I would like to work outside. Ride online while studying to pay the motorcycle installments" (P4)*

*"I want to study abroad and travel. I want to be away from her family, and she wants to do new things. I don't want to always be wealthy with her father and mother" (P5)*

*"My father wanted me to go to college, but I told him, sir, that college is difficult, and it's preferable to work to make money to give to my father and mother" (P6)*



### 3.2. Discussion

#### 3.2.1. Dealing with psychosocial problems and moral dilemmas

Based on the results of the analysis, all participants in this study revealed experiencing psychosocial problems and moral dilemmas they felt while living with a father with schizophrenia. Five out of six participants mentioned that they felt sad when they saw their father's behavior during his tantrums. Previous studies suggested [15] adolescents experience physical fatigue and difficulty regulating emotions when caring for family members with mental disorders, due to their memories of childhood with parents who often showed aggressive behavior when facing conflicts or problems which results in adolescents often feeling sad. Fear of parental symptoms, feeling lost and lonely, and lack of peace and happiness considered as triggers of developing aggressive behaviors among Schizophrenic parents [16].

Adolescents who have a father with schizophrenia have many responsibilities in the household, such as caring for their father and siblings so adolescents show feelings such as sadness, helplessness and sometimes even guilt [17]. One in six participants felt confused every time they faced their father who could not recover. These feelings were explained by children not being properly informed about parental mental health problems [17]. Many problems experienced by adolescents living at home with Schizophrenic fathers were compared to adolescents living with parents without mental disorders [1], [18]. Such issues make them feel stress which increases over a long period of time, causing a pessimistic attitude in adolescents. Problems of closeness between the mentally ill father and the child can also affect the child's emotional development.

#### 3.2.2. Lack of closeness between father and child

Five out of six participants revealed a lack of closeness between their fathers and children. Participants reported they no longer cared about their father because they were afraid to face them. The other participants expressed their hopes to be close to his father and be able to communicate by telling his life to his father. These results match previous research conducted by Buanasari *et al.* [1] which revealed that adolescents see their father as a different figure, so they feel lonely and long for a normal life with their father. Mental disorders experienced by their father cause conflict between children and fathers, so they tend to be quiet and inactive in their social environment because they do not want to attract the attention of their friends.

A participant in this study revealed that although he lived in the same house with his father, he was only spoken to in moderation such as reminding him to eat. The results of Evenson's research (2008) in Wong *et al.* revealed that fathers with schizophrenia more often choose to avoid physical contact with their children associated with feelings of shame for having mental disorders and they are very worried if their illness can be passed on to their children. Fathers are not afraid of losing custody and want to focus more on their treatment, they feel that their illness has damaged their relationship with their children because it affects them through diminishing energy levels, decreased concentration, and lack of ability to show emotions [19], [20].

#### 3.2.3. Exposures of violence inside and outside the home

In this study, five out of six participants revealed that they had experienced violence inside and outside the home from their family and friends. One participant revealed that he had experienced rejection and bullying from his mother's family because he did not accept his father's condition. Adolescents chose to limit themselves in sharing their difficulties with friends, family, or health workers. Such limitations result in a lack of openness that families with mental illness face the risk of living with shame, guilt, and social stigmatization, which causes them to hide their problems. Children learn early on to keep family situations secret, so they feel they can protect family members. This is supported by research from Trondsen [17] which says that children with mentally ill parents struggle to present themselves as someone "normal" and equal among their peer group to be able to avoid stigma. Similarly, Herbert *et al.* [21], the existence of negative stigma from society is an important part of the experience of growing up with a parent with mental illness. Stigma is experienced in the form of embarrassment in public, being made fun of by others, and fear of being considered by others as mentally ill.

Two participants said they had been victims of bullying from their schoolmates when they found out that their father had a mental illness, so the participants chose to be alone and keep their distance from their friends. The study findings are similar to research by Herbert *et al.* [21] who said they chose to hide as an option to avoid their environment and chose to cut ties with neighbors and relatives because of their father's mental illness. Three of the six participants in this study were revealed to have been victims of domestic violence from their father during relapse. There were two acts of domestic violence in the form of physical and psychological. In this study, participants received physical violent behavior such as kicks and punches from their father which can leave trauma. Participants also received psychological violence behavior, namely often being shouted at, and scolded without any cause, making participants feel afraid, helpless, and unable to fight back.

Based on a study conducted by Steven *et al.* [22], there are positive and negative symptoms caused by schizophrenia. They further discovered most Schizophrenic patients showed positive symptoms such as violent behavior. The causative factors that exacerbate violent behavior are insufficient economic conditions and the difficulty of changing the behavior of Indonesian society, namely, the view men are higher than women [23]. The situation is consistent with the conditions experienced by the participants' fathers, all of whom came from low socioeconomic backgrounds. His father could not work to support the family because he had schizophrenia with positive symptoms and had difficulty controlling violent behavior.

#### **3.2.4. Getting the wisdom behind the catastrophe**

Based on the results of the study, participants in this study revealed that their father's condition made them more patient and grateful, which made them closer to God. These results are supported by Kahl and Jungbauer [18] which says that adolescents who live with fathers with schizophrenia, because they are often faced with conflicts and problems, develop coping strategies that are different from their.

Another participant said he loved his father more and wishing for his father to have a longer life. This is in accordance with the research of Kahl and Jungbauer [18] found that among many problems faced by adolescents who have fathers with schizophrenia, it does not result in the loss of feelings of affection and trust in the relationship between children and parents.

One participant said he became more independent and more appreciative of his father. This is in accordance with the research of Herbert *et al.* [21] where it was stated that when adolescents have parents with mental illness, they feel positive learning such as becoming more independent because they feel that they can handle things themselves, and develop positive thinking in accepting and providing help, so they feel that this experience makes them selfless. This is supported by Ribé *et al.* [24] who revealed that adolescents do not care about physical complaints and the burden they feel when caring for their parents and continue the care their parents need.

All participants in this study were Muslim and five out of six participants in this study said they could survive because they believed in God, so they believed they were able to carry out their destiny and accept their father's condition. They try to motivate themselves to be stronger with the faith they have. This situation is in accordance with findings of study conducted by Hernandez and Barrio [25], that religion, faith and spiritual practices can control emotions and help a person to relate well and be more responsible in caring for patients with mental disorders.

#### **3.2.5. Changing roles and responsibilities**

Based on the results of the study, five out of six participants mentioned that they became the breadwinner for their family because they were sad that their father could not work. Participants also revealed that they felt responsible for their father's care and helped their father when he relapsed and wanted to take medication. Trondsen [17] research revealed that although passive adolescents live their daily lives full of challenges; they are active and competent actors in their efforts to manage their respective family situations. They are active participants in handling their family life by taking on household responsibilities, caring for their siblings, and trying to organize time off when their emotions are difficult to control.

#### **3.2.6. Lack of social support**

As a result of the study, four out of six participants revealed a lack of social support from the people around them. Two participants needed support from relatives from their father's family, such as wanting to be visited, not feeling ashamed of having relatives with schizophrenia so that their father could be cared for by his extended family. One participant needed support from his siblings to care for his family together. This study is in accordance with Trondsen [17] and Herbert *et al.* [21] that support from family members, friends, and relatives is the most important thing for adolescents to help them overcome difficulties, apart from positive distraction and religious coping. The need for the availability of support systems such as health services that can play an important role in the lives of adolescents, such as the need for information about explaining their parents' illness by being able to explain the reasons for their parents' behavior so that they can understand their parents' conditions and regulate emotions that can be painful for them.

#### **3.2.7. Difficulties in sharing personal issues**

Based on the results of the study, five of the six participants revealed that they had difficulty expressing their feelings and problems as a result of not wanting to tell others about their condition. The first participant said that no one knew about his father's condition at school and did not tell his mother because he felt that his mother's condition was harder than his condition. The second participant stated that he chose not to tell his problem because he felt it was not natural to be known by others and considered things that happened in his family to be private. The third participant reported that he felt ashamed of his father's condition so he

chose not to tell his father's condition to others. The last participant chose to suppress his problem because he felt that his condition would not be easily understood by others [18].

This is in accordance with a recent study by Buanasari *et al.* [1], which revealed that mental disorders experienced by their fathers caused conflict between children and fathers, so they tend to keep private and inactive in their environment because they do not want to attract the attention of their friends. During the emerging adulthood period, most adolescents find it difficult to socialize and regulate emotionally. They also tend to avoid social activities and do not have many friends at school because they are afraid that their friends know about their parents' condition which will make adolescents feel embarrassed [1], [17], [18], [24], [26], [27]. The occurrence of social problems is caused by physical health related to the quality of life that they have to care for fathers with schizophrenia, making them often feel fatigued [28]

### 3.2.8. Seeking to build a better future

The literature revealed that the impact of a mentally ill parent on adolescents can increase the risk of these children developing mental illness themselves. There are even more reasons to worry about the condition of adolescents as they grow up (Trondsen). Adolescents feel disappointed during their childhood as they often feel rejection from parents and are not heard and taken seriously or understood, which will cause doubts about their future [21], [29]. This is different from the results found by the researcher, that all participants in this study tried to build a better future in work. In the field of work, participants want to be successful in their careers because it can make their parents feel proud and happy. Other participants have received many failures in getting a job but it did not make them give up.

There is an influence of Indonesian culture which notably is a collective culture (Hofstede) that gives an overview of the position of parents. Parents are a social group that is respected and valued. In the Javanese ethnic group, the elderly are seen as entitled to a high level of respect, and many live out their lives solely on the receiving end of this respect [30]. The lives of the elderly are generally peaceful. They are very helpful in nurturing the children in the family, and there is usually a warm and cordial relationship between the older and younger members of the household. In traditional societies, which generally consist of extended families, entering old age is not a cause for concern. They are best served by their children and other siblings. Children still feel obliged and loyal to support their parents who are no longer able to take care of themselves. The value still prevails in society that children are obliged to give affection to their parents as they had received when they were young [30].

## 4. CONCLUSION

Although living with a schizophrenic father makes it more likely for the children to experience several negative effects, the adolescents still have opportunities to continue building a better future. Improving health promotion and education programs to manage negative emotions and developing Self-Help Groups for adolescents whose fathers have schizophrenia is thus necessary. Further study should determine effective interventions to manage mental health problems among adolescents whose fathers were diagnosed with schizophrenia.

## ACKNOWLEDGEMENTS

The researchers thanked all participants involved in this study and in particular, the coordinator of Mental Health Program at *Puskesmas* Babakan Sari who facilitated this research.





## REFERENCES

- [1] A. Buanasari, N. Helena, C. Daulima, and I. Y. Wardani, "The experience of adolescents having mentally ill parents with pasung," *Enfermería Clínica. Enfermería Clínica*, vol. 28, pp. 83–87, 2018.
- [2] A. E. Reupert, D. J. Maybery, and N. M. Kowalenko, "Children whose parents have a mental illness: Prevalence, need and treatment," *MJA Open*, vol. 1, no. 1, pp. 7–9, Apr. 2012, doi: 10.5694/mjao11.11200.
- [3] B. A. LeFrançois, "Distressed fathers and their children: A review of the literature," *International Journal of Social Psychiatry*, vol. 58, no. 2, pp. 123–130, Mar. 2012, doi: 10.1177/0020764010387478.
- [4] O. Wong, T. Nguyen, N. Thomas, F. Thomson-Salo, D. Handrinis, and F. Judd, "Perinatal mental health: Fathers – the (mostly) forgotten parent," *Asia-Pacific Psychiatry*, vol. 8, no. 4, pp. 247–255, Dec. 2016, doi: 10.1111/appy.12204.
- [5] I. M. A. Siagian, "Life experiences of adolescents living with mothers with schizophrenia in Bandung city," (in Indonesian), Thesis, Universitas Padjadjaran, 2020.
- [6] WHO, "Schizophrenia," *World Health Organization*, 2022. [Online]. Available: <https://www.who.int/news-room/fact-sheets/detail/schizophrenia> (accessed Jan. 15, 2023).
- [7] D. Yadav, "Criteria for Good Qualitative Research: A Comprehensive Review," *Asia-Pacific Education Researcher*, vol. 31, no. 6, pp. 679–689, 2022, doi: 10.1007/s40299-021-00619-0.




- [8] J. W. Creswell, "Research design: qualitative, quantitative and mixed methods approaches: fourth edition," *Sage Publications*, vol. 1, 2014.
- [9] S. S. Zhou, L. Z. Wei, W. Hua, X. C. He, and J. Chen, "A qualitative study of phenomenology of perspectives of student nurses: experience of death in clinical practice," *BMC Nursing*, vol. 21, no. 1, pp. 1–11, 2022, doi: 10.1186/s12912-022-00846-w.
- [10] Praveena K.R and Sasikumar S, "Application of Colaizzi's method of data analysis in phenomenological research," *Medico Legal Update*, vol. 21, no. 2, pp. 914–918, 2021, doi: 10.37506/mlu.v21i2.2800.
- [11] R. Morrow, A. Rodriguez, King, and Nigel, "Colaizzi's descriptive phenomenological method original citation," *The Psychologist*, vol. 28, no. 8, pp. 643–644, 2015.
- [12] W. H. Susilo, C. I. Kusumaningsih, H. Aima, and J. Hutajulu, *Qualitative research and nursing science research applications*. (in Indonesian), Jakarta: CV. Trans Info Media, 2015.
- [13] B. FitzPatrick, "Validity in qualitative health education research," *Currents in Pharmacy Teaching and Learning*, vol. 11, no. 2, pp. 211–217, 2019, doi: 10.1016/j.cptl.2018.11.014.
- [14] S. K. Ahmed, "The pillars of trustworthiness in qualitative research," *Journal of Medicine, Surgery, and Public Health*, vol. 2, p. 100051, 2024, doi: 10.1016/j.glmedi.2024.100051.
- [15] N. A. Stahl and J. R. King, "Expanding approaches for research: understanding and using trustworthiness in qualitative research," *Journal of Developmental Education*, vol. 44, no. 1, pp. 26–28, 2020, doi: 10.4135/9781483329574.
- [16] E. De la Serna *et al.*, "Lifetime psychopathology in child and adolescent offspring of parents diagnosed with schizophrenia or bipolar disorder: a 2-year follow-up study," *European Child & Adolescent Psychiatry*, vol. 30, no. 1, pp. 117–129, Jan. 2021, doi: 10.1007/s00787-020-01500-z.
- [17] M. V. Trondsen, "Living with a mentally ill parent: Exploring adolescents' experiences and perspectives," *Qualitative Health Research*, vol. 22, no. 2, pp. 174–188, 2012, doi: 10.1177/1049732311420736.
- [18] Y. Kahl and J. Jungbauer, "Challenges and Coping strategies of children with parents affected by schizophrenia: results from an in-depth interview study," *Child and Adolescent Social Work Journal*, vol. 31, no. 2, pp. 181–196, 2014, doi: 10.1007/s10560-013-0316-2.
- [19] E. Evenson, J. Rhodes, J. Feigenbaum, and A. Solly, "The experiences of fathers with psychosis," *Journal of Mental Health*, vol. 17, no. 6, pp. 629–642, 2008, doi: 10.1080/09638230701506259.
- [20] K. M. Mitchell *et al.*, "The potential effect of COVID-19-related disruptions on HIV incidence and HIV-related mortality among men who have sex with men in the USA: a modelling study," *The Lancet HIV*, vol. 8, no. 4, pp. e206–e215, Apr. 2021, doi: 10.1016/S2352-3018(21)00022-9.
- [21] H. S. Herbert, M. Manjula, and M. Philip, "Growing up with a parent having schizophrenia: Experiences and resilience in the offsprings," *Indian Journal of Psychological Medicine*, vol. 35, no. 2, pp. 148–153, 2013, doi: 10.4103/0253-7176.116243.
- [22] T. M. Steven M. Silverstein, Jill Del Pozzo, Matthew Roché, Douglas Boyle, *Schizophrenia and violence: realities and recommendations*, 1st Editio. 2020.
- [23] N. Y. Simbolon, E. Ediwarman, M. Ablisar, and R. Rosmalinda, "Factors affecting the relationship of domestic violence perpetrators," *Proceedings of the 1st International Conference on Social Science (ICSS)*, vol. 2, no. 1, 2023, pp. 170–176, doi: 10.59188/icss.v2i1.103.
- [24] J. M. Ribé, M. Salamero, C. Pérez-Testor, J. Mercadal, C. Aguilera, and M. Cleris, "Quality of life in family caregivers of schizophrenia patients in Spain: caregiver characteristics, caregiving burden, family functioning, and social and professional support," *International Journal of Psychiatry in Clinical Practice*, vol. 22, no. 1, pp. 25–33, 2018, doi: 10.1080/13651501.2017.1360500.
- [25] M. Hernandez and C. Barrio, "Perceptions of subjective burden among latino families caring for a loved one with schizophrenia," *Community mental health journal*, vol. 51, no. 8, pp. 939–948, Nov. 2015, doi: 10.1007/s10597-015-9881-5.
- [26] G. Stacey and M. Pearson, "Exploring the influence of feedback given by people with lived experience of mental distress on learning for preregistration mental health students," *Journal of Psychiatric & Mental Health Nursing (John Wiley & Sons, Inc.)*, vol. 25, no. 5/6, p. 1, Jun. 2018, doi: 10.1111/jpm.12465.
- [27] E. De la Serna *et al.*, "Lifetime psychopathology in child and adolescent offspring of parents diagnosed with schizophrenia or bipolar disorder: a 2-year follow-up study," *European Child and Adolescent Psychiatry*, vol. 30, no. 1, pp. 117–129, 2021, doi: 10.1007/s00787-020-01500-z.
- [28] H. Alataş and N. Arslan, "Sleep, malnutrition, and quality of life in elderly hemodialysis patients: A cross-sectional study," *Médecine Palliative*, vol. 22, no. 5, pp. 260–268, 2023, doi: 10.1016/j.medpal.2023.06.008.
- [29] K. Dam and E. O. C. Hall, "Childhood experiences pursue adulthood for better and worse: a qualitative study of adults' experiences after growing up with a severely mentally ill parent in a small-scale society," *Journal of Research in Nursing*, vol. 25, no. 6–7, pp. 579–591, 2020, doi: 10.1177/1744987120942272.
- [30] S. Sulandari, R. O. Coats, T. Taufik, and J. Johnson, "What does it mean to 'age well' among british and javanese older adults? A cross-cultural qualitative study," *The Journals of Gerontology: Series B*, vol. 79, no. 7, p. gbac085, Jul. 2024, doi: 10.1093/geronb/gbac085.

## BIOGRAPHIES OF AUTHORS






**Sarah Kusumah Bakti**     is a mental health nurse and researcher, is a lecturer in mental health nursing. Sarah received a Bachelor's degree in Nursing and Professional Nursing from 'Aisyiyah University Bandung, a Masters in Nursing with a psychiatric specialization from Padjadjaran University. She is a full-time lecturer at lecturer at Yaspen Nursing Academy Jakarta. Her research focuses on Psychiatric nursing. She can be contacted via email: sarahkusumahbakti@gmail.com.






**Hana Rizmadewi Agustina**    is a nurse educator held PhD in Nursing Studies from the University of Nottingham, United Kingdom. She is a full-time lecturer at Department of Fundamental and Pediatric Nursing Faculty of Nursing Universitas Padjadjaran, and as a guest lecturer at the Faculty of Medicine and Allied Health Sciences in Universitas Padjadjaran and as an active member of several professional organizations (e.g., Indonesia National Nurses Association of West Java Province, the Association of Indonesian Oncology Nurses (HIMPONI) of West Java Province. Her research focuses on fundamental nursing, nursing education, and curriculum development, palliative and end of life care, and nursing management. She also acts as a peer reviewer of several international journals. She can be contacted via email: hana.rizmadewi@unpad.ac.id.






**Aat Sriati**    is a lecturer at the Department of Mental Nursing, Faculty of Nursing, Universitas Padjadjaran since 1996. Completed the Master's Program in Developmental Psychology at the Faculty of Psychology, Universitas Padjadjaran in 2008. Areas of communication expertise in nursing, psychosocial aspects, and complementary therapies. Have publication experience in national and international journals, including Effect of Assertiveness Training to Reduce Anger in Patients at Risk of Violence Behavior: A Literature Review, Relationship Between Self-Control of Smartphone Use and Cyberbullying Behavior among University Student, Relationship Between Self-Control of Smartphone Use and Cyberbullying Behaviour among University Student, The Balance of Spiritual and Nutritional Needs Improves the Well-Being of Cancer Patient during Chemotherapy. She can be contacted at email: aat.sriati@unpad.ac.id.



**Suryani**    is the first professor at the Faculty of Nursing, Universitas Padjadjaran. Currently, she is a head of the Mental Health Department at the Faculty of Nursing. Suryani has done many research in the area of psychiatric mental health nursing. Her current project is 'Model recovery of people with schizophrenia in Indonesia and developing model for preventing and overcoming internet addiction among adolescent in West Java, Indonesia. She was a chief editor of *Jurnal Keperawatan Padjadjaran* and she has been a reviewer of some international Journals. She can be contacted at email: suryani@unpad.ac.id.



**Noureen Asif Shivji**    as a Research Associate in applied Qualitative Health Research in April 2019, and has an active research role within the university. Noureen graduated as a Registered Nurse in 2005 from the Aga Khan University (AKU), School of Nursing and Midwifery (SONAM), Karachi, Pakistan, and practiced initially as a Critical Care Nurse and later as Clinical Nurse Instructor in Post Anaesthesia Care Unit of the AKU hospital. She then went to undertake her post-graduate qualifications from the University of Western Australia, Perth, Australia, after being awarded an Australian Development Scholarship from AusAid and finished her Master's in Public Health (Nursing) in 2010 with Distinction. Noureen commenced her PhD at the University of Nottingham, after being awarded a Vice Chancellor's International Research Excellence scholarship. She can be contacted at email: n.shivji@keele.ac.uk.