

FAMILY EXPERIENCES IN CARING FOR ADOLESCENT WITH MENTAL DISORDERS: A QUALITATIVE STUDY

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Abstract

Purpose: The purpose of this study was to describe the experience by family caregiver of adolescent with mental disorders.

Methodology: This study was a qualitative study with phenomenological approach. The participants were fifteen family caregiver of adolescent with mental disorder. Interviews were semi-structured and ranged from forty-five minutes to one hours. Data were analyzed using collaizi method.

Findings: This study found eight emerged theme from family experience in caring for adolescent with mental disorders. The themes were *Barriers to health-seeking behavior; Facilitator to health-seeking behavior; lack of adolescent involvement in treatment; hide the condition of teenagers from others; challenges in social life of adolescent; challenges in academic achievement of adolescent; Family efforts to care for adolescents with mental disorders; and Family hope for adolescent with mental disorder.*

Limitation: This study have limitation that only interviewing the experiences of one of family caregiver, so that the point of view of a adolescent with mental disorder and other family members is limited.

Contribution: This study highlighted the needs of mental health education program to increase parent, school, peer and adolescent literacy; collaborate to offer effective help to adolescent with serious mental health problems in academic area, and adolescent involvement in the treatment process should be enhanced in family of adolescents with mental disorder to reach optimal recovery.

Keywords: *psychosocial mental health nursing; adolescents; recovery; mental disorder*

1. Introduction

The number of people with mental disorders in the world is 450 million people with the largest percentage of contributors to the burden of disease being mental disorders (14.4%), in Indonesia it is 13.4% (1). One in 10 children aged 5-16 years is diagnosed with a mental health problem (Royal College of Nursing, 2016) with 10-20% of adolescents experiencing *underdiagnosed* and *undertreated* (Viora, 2018). In Indonesia, According to RISKESDAS 2018, more than 19 million people aged over 15 years experienced mental and emotional disorders, and more than 12 million people aged over 15 years experienced depression (Biro Komunikasi dan Pelayanan Masyarakat, 2021). At the age of adolescents (15-24 years) have a depression percentage of 6.2%.

Parents and caregivers had an important role to put on contact of their children to mental health care, often acting as gatekeepers to accessing professional services (Reardon et al., 2018), helping children grow and develop to their full potential (Ambikile & Outwater, 2012) and in

supporting them through prolonged periods of recovery. Prior study stated that parents of children with chronic illness report various levels of social, financial and emotional burdens (Angold et al., 1998). Parents and caregivers of adolescent with emotional and behavioural disorders often experience significant burden associated with care of the child. The problem of health services in Indonesia is related to mental health services in the form of a gap in inadequate mental health facilities (Idaiani & Riyadi, 2018; Leijdesdorff et al., 2021), lack of mental health human resources (R.D. Tristiana et al., 2018), delays in diagnosis and seeking health care, stigma and discrimination against people with mental disorders cause delays in access to mental health facilities (Lal & Malla, 2015; R.D. Tristiana et al., 2018), and treatment gaps (Idaiani & Riyadi, 2018).

Adolescents with personal and social development disorders have a high risk of experiencing mental disorders as adults which will affect their opportunities to obtain education and employment and in the long term have negative consequences for health, economy, social and quality of life (Palmquist et al., 2017). An important issue that faces adolescent with mental health problems is the negative social stigma associated with mental illness.

Recovery has become a prominent concept in the scientific literature and policies on mental health. Prior study found that it is appropriate and valid to use ‘recovery’ in the treatment process for adolescents. However, while adults share various facets of the recovery process with their adolescent counterparts, there are also significant differences such as physiological change, the impact of peers, identity development and the role of family (Ward, 2014). Other study also highlighted the need for a more clear focus on healthcare services role and participation in adolescent’s recovery processes, at the same time as family involvement needs to be further investigated and operationalized (Moberg et al., 2022).

2. Literature review and hypotheses development

Prior research that explored family role in enhancing recovery in adolescent with substance abuse found that family enhance adolescent recovery through *assessment support, instrumental, informational, and social* (Sari et al., 2021). *Parent’s role in enhancing recovery toward adolescent with mental disorder need to be explored.* The purpose of this study was to describe the experience by family caregiver of adolescent with mental disorders especially in promoting adolescent recovery and caring for adolescent with mental disorder.

3. Research methodology

Design

This study was a qualitative study with phenomenological approach.

Participants

Study participants were parents or family caregiver of adolescents with mental disorder. The recruitment process was offered via social media. The sampling method used purposive sampling. For inclusion: parents or family caregiver of adolescents (10-24 years), Bahasa language capability and agree to be participant of the study.

Data Collection

Two participants were pre-interviewed to determine the outline of the interview. Due to isolation, prevention of epidemic, and control requirements, interviews were conducted by telephone, whatsapp voice, or face-to-face. Interviews were semi-structured and ranged from forty-five minutes to one hours. At this time, expectations regarding time commitment, audio taping, consent process, and storage of collected data were discussed and potential risks and benefits of the study were identified. The participants were assured of their right to terminate their involvement at any time during the process and their ability to contact the researcher at any time by telephone. Consent forms were signed.

Table 1 Semi-structured interview questions

Question
1. Please describe about your experience in caring for client since the client first appeared symptoms and was taken to a health facility related to mental problems?
2. Please describe about the difficulties and challenges you have faced and how to overcome them?
3. Please describe about your experience with family, friends and neighbors around the house regarding the client's condition?
4. Please describe the meaning of heal/recover from mental disorders for you?
5. Please describe how did you do to achieve the recover condition of the client?
6. Please describe about your hopes and desires regarding the client's condition?

Data analysis

Data were transcribed immediately after the interview finished and analyzed using Colaizzi's method. Colaizzi's analysis is divided into seven step namely: (1) Reading and re-reading the verbatim materials to obtain general understanding of the research object; (2) Extracting statements related to the research problem; (3) Summarizing, extracting and encoding the extracted data; (4) Summarizing the encoded ideas and seeking common concepts to form themes and theme groups; (5) Performing a detailed description of the relationship between the theme and the research object; (6) Stating the essential structure that constitutes the phenomenon; (7) Returning the final analysis to the research object for verification. Two researchers independently analyzed, coded, summarized, and refined the interview materials to form primary and secondary themes. Discrepancies were solved by discussions and coming to consensus with experienced peers within the research team. participants were contacted via telephone if doubts arose during data confirmation.

4. Results and discussions

The number participants in this study was 15. The relationship of participants with client were sister (2 participants), mother (8 participants), father (3 participants) and grandmother (2 participants).

Table 2 Demographic characteristics of participants

Participants	Gender	Age (year)	Education level	Jobs	Relation with patients	Diagnosis of patients	Patient's age
P1	Female	23	Senior high school	College's Student	sister	Schizophrenia	17

P2	Female	45	Senior high school	Housewife	Mother	Depression	16
P3	Female	39	Senior high school	Housewife	Mother	Anxiety	16
P4	Male	51	Bachelor's degree	Employer	Father	Depression	15
P5	Female	40	Senior high school	Housewife	Mother	Anxiety	18
P6	Female	38	Senior high school	Housewife	Mother	Anxiety	18
P7	Female	43	Senior high school	Housewife	Mother	Depression	17
P8	Female	62	Junior high school	None	Grandmother	Schizophrenia	15
P9	Male	45	Bachelor's degree	Employer	Father	Anxiety	16
P10	Female	41	Senior high school	Employer	Mother	Anxiety	17
P11	Female	28	Senior high school	Employer	Sister	Anxiety	15
P12	Male	49	Senior high school	Employer	Father	Depression	16
P14	Male	30	Bachelor's degree	Employer	Brother	Depression	15
P15	Female	51	Senior high school	Housewife	Mother	Depression	17

Theme 1 Barriers to health-seeking behavior

The results of the theme analysis found that the theme of parental and caregiver barriers in health-seeking behavior is the category of parental knowledge deficit about mental problems in adolescents, negative attitudes of parents about mental problems, community stigma. The lack of knowledge of parents or caregivers about mental problems in adolescents that causes delays in examinations in health services is found from the statement:

"...the symptoms are visible...but the family doesn't understand the problem (mental problem)" (sister, 23 years old)

"At first I thought it was my child's behavior when there was a problem, I just let it go, I didn't know that my child was sick like that" (mother 45 years)

Barriers to health-seeking behavior, namely negative attitudes of parents about mental problems conveyed by participants:

"In my heart it was like when I had a psychological problem, but I dismissed that thought, I didn't believe it, so I took it to a smart person, I was afraid if it really did (suffering from mental problems)" (mother 39 years old)

"...the client is taken to a psychologist who tests his/her interest/aptitude... my parents did not believe that my brother was sick" sister 23 years old

"My child is a strong child, it is impossible for my child to be mentally ill, at that time I did not .. like it is impossible for my child to have a weak mind, like that" (father, 51 years old)

Barriers to health-seeking behavior, namely the still high stigma from the community about mental problems conveyed by participants:

"It's like I'm afraid if it's true (suffering from mental problems), people will definitely blame me and my husband and then they look bad" (mother 40 years old)

"There are also next door neighbors who are disturbed, that's really being avoided, I'm afraid to be treated the same as them" (mother 38 years old)

Theme 2 Facilitator to health-seeking behavior

The results of the analysis show that the themes that encourage parents and caregivers in seeking help behavior are symptoms that are increasing towards violence, suggestions from other people who are considered competent, requests from teenagers, literacy of parents or caregivers

about mental problems. parents and caregivers bring clients to health services when the client shows dangerous behavior and the symptoms shown are increasing, this is as stated by the participants as follows:

“When he started attacking his mother, father, and getting worse, it was only then that he was taken to a psychologist, who was eventually referred to a psychiatrist” (sister, 23 years old)

“His head was banging against the wall, I shouted to stop but instead he said rudely and hit me, finally I asked the neighbors in front of the house to take me to the hospital” (mother 43 years old)

“The tantrums at home kept running out and beating the neighbors, so they were taken to the hospital” (grandmother 62 years old)

The motivators for parents and caregivers in seeking help are suggestions from other people who are considered competent as conveyed by participants:

“At first, you were adamant that you didn't want to take him to the hospital. At that time, the nurse, who happened to be the nurse, said that you had ordered him to see a psychiatrist before it got worse. After being told, you finally wanted to take him to the hospital”(Sister 28 years old)

“At that time I told the ustadz (religion figure) in my area, he was asked to be examined by a doctor as well so that the medical and spiritual path would be like that” (father 45 years old)

The driving force for parents and caregivers in seeking help behavior is requests from adolescents, as conveyed by participants as follows:

“The child said, Ma, I feel really sad, I'm afraid, Mom, it's like I'm not alone, then at first I just gave motivation, but how come this child seems so unpredictable, sometimes suddenly cries, and often invites me to check, finally I went to the doctor...” (Mother 39 years old)

The driving force for parents and caregivers in seeking help behavior is parental or caregiver literacy about mental problems as conveyed by participants as follows:

“Yes, I often follow the news (about mental problems), read on social media, chat with relatives who happen to be health people, when my child seems to change, although at first I thought there might be a problem again, but how come it's getting worse, like I don't want to? out of the room, then finally he screamed in the room, I immediately took him to the doctor” Father 49 years old

Theme 3 lack of adolescent involvement in treatment

The third theme is the behavior of parents or caregivers who do not involve adolescents in the treatment process, namely not conveying the illness suffered by adolescents to adolescents who have mental problems, adolescents are less involved in control activities and taking medication. The behavior of parents or caregivers that does not involve adolescents in the treatment process is not conveying the illness suffered by adolescents to adolescents who have mental problems, as conveyed by participants as follows:

“...My brother (client) was informed about his illness recently (since he was diagnosed more than 1 year, the family still doesn't accept it).” (sister 23 years old)

"I didn't tell you, I was afraid that the child would be okay, so I said it's okay, it's just an ordinary illness, the important thing is not to be stressed and to be diligent in taking medicine"
(Mother 41 years old)

The behavior of parents or caregivers who do not involve adolescents in the treatment process, namely adolescents are less involved in control activities and taking drugs, as conveyed by participants as follows:

"...every control my mother came... told the doctor about her behavior, while the younger brother didn't come..." (sister 23 years old)

"If I take control and take my own medicine, I'm sorry if I meet a friend or neighbor at the hospital later" Mother 37 years old

"Just take the medicine, the child never comes, except when he has a fever"
Grandmother 58 years old

Theme 4 hide the condition of adolescents from others

The results of data analysis showed that the behavior of parents and caregivers hides the condition of adolescents from others, hides the condition of adolescents from school friends, hides the condition of adolescent clients from neighbors. Parents and caregivers hide the condition of teenagers who have mental problems from their school friends as stated by the participants as follows:

"Parents only told the homeroom teacher about the condition of the younger brother, but they were asked not to tell his friends" (sister 23 years old)

"Yes, I didn't say it, Ms. (to my school friends), only to the homeroom teacher, if my child has a psychological problem, I can't bear it later, his friends will be strange to my child" (mother 38 years old)

Parents and caregivers hide the condition of adolescents who experience mental problems from neighbors as stated by participants as follows:

"When a client attacks a neighbor, a family who apologizes but doesn't tell his sister's condition, because he is cornered and bullied ..." (sister 23 years old)

"Yes, I didn't say anything to the neighbors, because I was afraid that it would be gossip"
(mother 40 years old)

Theme 5 challenges in social life of adolescent

The difficulties experienced by adolescents who experience mental problems face difficulties in their social life, namely the difficulty of building relationships with other people, being shunned by some school friends. The difficulties experienced by adolescents who experience mental problems face difficulties in their social life, namely the difficulty of building relationships with other people as stated by the participants as follows:

"...to mingle with people (clients) having trouble... so often stay at home" (23 years old sister)

The difficulties experienced by adolescents who experience mental problems face difficulties in their social life, namely being shunned by some school friends, as stated by participants as follows:

"...there are friends who accompany but there are also those who don't want to be close..." (23 years old sister)

"... the brother vented to his friend via whatsapp..." (23 years old sister)

Theme 6 challenges in academic achievement of adolescent

The challenges experienced by adolescents with mental health problems are in academic achievement in the form of difficulty focusing on learning at school. The challenges experienced by adolescents with mental health problems are academic achievement in the form of difficulty focusing on learning at school, as stated by participants as follows:

"clients continue their activities as usual but clients become unable to focus on learning" (23 years old sister)

The challenges experienced by adolescents with mental health problems are in academic achievement in the form of parents and caregivers replacing doing client tasks, as stated by participants as follows:

"Some of the client's tasks are helped by my mother, because when my sister has a lot of tasks, it sometimes relapses..." (sister 23 years old)

Theme 7 Family efforts to care for adolescents with mental disorders

Families seek to increase knowledge by seeking information from social media about associations or organizations that deal with mental problems in adolescents as stated by participants as follows:

"...mother is looking for information from the Indonesian Schizophrenia Union in Facebook...but not a group in the real world..." sister 23 year old

Theme 8 Family hope for adolescent with mental disorder

Expectations of parents and caregivers on adolescents who experience mental problems, namely independent clients and knowing the illness they are suffering from, stigma in society on adolescents with mental problems can decrease.

"My hope is that my sister will be normal again, know what the pain is and be independent..." sister 23 year old

"...so that people around you don't give a negative stigma to mental disorders" sister 23 years old

"...clients are able to take a shower, eat alone even though sometimes it's not clean..." sister 23 year old

DISCUSSION

The purpose of this study was to describe the experience by family caregiver of adolescent with mental disorders especially in promoting adolescent recovery and caring for adolescent with mental disorder. The study found that parent experience barriers in health-seeking behavior such as parental knowledge deficit about mental problems in adolescents, negative attitudes of parents about mental problems, and community stigma. The results of this study found that parents have less

knowledge about psychiatric problems so they do not immediately bring teenagers to get treatment. The results of previous studies stated that (Villatoro et al., 2018) the individual's inability to recognize symptoms or problematic behavior will interfere with the process of seeking help behavior where problem recognition is the first order before deciding to seek help and choose treatment.

Parents' negative attitudes about mental problems in adolescents also prevent parents from seeking help. Parents still have negative views toward people with mental illnesses. There are still limited references about mental help-seeking among Indonesian population. Previous study found that most (78.3%) parents had negative attitude to childhood psychiatric disorders (Habib, 2020). Parental attitudes are an important factor in adolescents seeking help because adolescents depend on their parents to take them to health facilities (Wang et al., 2004). The study also found that increased symptoms shortened the time parents took their children to a health facility. This finding showed that healthcare team should conduct health education program to enhance mental health literacy for parents. The education is hoped could develop a more positive parent's attitude to psychiatric disorders including childhood psychiatric disorders which will lead to reduction in childhood psychiatric disorders and later adversities.

The results of previous studies stated that stigma on psychiatric problems affects parents' mindsets, so that when children show symptoms of mental problems, parents tend to consider their children's behavior as normal behavior to protect their families and adolescents are labeled or stigmatized by others. Denying the child diagnosis is a form of loss and grief (Richardson et al., 2013). Such grief may negatively affect family members' physical and psychological health and also the relationship with their relative. This finding showed that healthcare team should encourage parents to deal with the emotions and responses they face regarding their child's diagnosis.

Stigma in society against people with mental problems is still widely found. The results of previous studies indicate that stigma from society is an obstacle for clients and families in carrying out health care (Rr Dian Tristiana et al., 2018)

This study also found that the facilitator of parents to seeking help behavior are symptoms that are increasing towards violence, suggestions from other people who are considered competent, requests from teenagers, literacy of parents or caregivers about mental problems. Parents are less likely to take their child with them even though they know that their child is showing symptoms of the disorder. When the symptoms of the disorder get worse and start to bother people around the child, such as violent behavior, self-injury, parents tend to take their child to health services. This is what causes adolescents with mental problems to be diagnosed late and treated too late. These findings indicate the importance of increasing parental knowledge in recognizing and dealing with mental disorders in adolescents.

This study found that parents or caregivers still did not involve adolescents with mental problems with the treatment they received. Most parents and caregivers do not tell teenagers about the illness suffered by the teenager because they are afraid that it will add to the psychological burden of the teenager. Prior study found that engaging adolescent in activities with a focus on relatedness, autonomy and competence may have specific therapeutic potential (Stanton et al., 2020). Adolescent autonomy to engage with treatment should be based on the personal goals and values of each adolescent client as part of recovery (Lavik et al., 2018).

Parents and caregivers hide the condition of adolescents from others, hides the condition of adolescents from school friends, hides the condition of adolescent clients from neighbors. This disclosure is caused by the public and self-stigma of mental illness (Buchholz et al., 2015). This finding highlighted that healthcare services need to develop program that assess the parent' perceptions about mental illness and their ability in communicate about mental health issue.

The difficulties experienced by adolescents who experience mental problems face difficulties in their social life, namely the difficulty of building relationships with other people, being shunned by some school friends. Peer relationships help the adolescent find ways to overcome issues they are facing. Friendships did play a positive role in the children's ability to socially adjust but only if the friend was supportive (Adkins, 2019).

The challenges experienced by adolescents with mental health problems are in academic achievement in the form of difficulty focusing on learning at school. The challenges experienced by adolescents with mental health problems are academic achievement in the form of difficulty focusing on learning at school. the social consequences of mental health problems are not the inevitable result of diminished functional ability but, rather, reflect negative social responses (McLeod et al., 2012). Mental distress has been linked to lower academic self-efficacy and poor study progress (Grøtan et al., 2019). School should collaborate with parents and health services to make it possible to offer effective help to students with serious mental health problems.

Expectations of parents and caregivers on adolescents who experience mental problems, namely independent and knowing the illness they are suffering from and stigma in society on adolescents with mental problems can decrease.

5. Conclusion

This study highlighted that healthcare team should conduct health education program to enhance mental health literacy for parents to develop a more positive parent's attitude to psychiatric disorders; encouraging parents to deal with the emotions and responses they face; increasing parental knowledge in recognizing and dealing with mental disorders in adolescents; assess the parent' perceptions about mental illness and their ability in communicate about mental health issue; collaborate with parents and health services to make it possible to offer effective help to students with serious mental health problems; and the needs of adolescent involvement in the treatment process should be enhanced in family of adolescents with mental disorder to reach optimal recovery.

Limitation and study forward

This research has the limitation of not exploring the whole family and only exploring one family member so that the information provided is purely from one family's point of view. Further research needs to add other family members who are also caregivers for adolescents with mental disorders to obtain more complete and complete information

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