

ORIGINAL PAPER

Caring for a Family Member With Schizophrenia: The Experience of Family Carers in Indonesia

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Abstract

Introduction: Schizophrenia is a chronic and severe mental illness which is characterized by cognitive impairment, difficulty in engaging in daily social activities and the challenges of securing and maintaining employment. These conditions have the capacity to significantly impact on quality of life for family members. By ignoring this situation, family members continue to be overburdened with care responsibilities, and mental health professionals continue to be unable to address the needs of the family and the family member living with schizophrenia. Therefore, a deeper understanding of the experience of Indonesian family members in providing care to a family member with schizophrenia at home is important as understanding this phenomenon can inform the provision of quality appropriate family-centered care. **Aim:** To gain an understanding of the experiences of Indonesian family carers in providing care to a family member with schizophrenia at home. **Method:** This study was recently carried out in West Java, Indonesia. Nine primary caregivers were selected, and data were collected through two individual face-to-face in-depth interviews with each participant. Analysis of participant transcripts was undertaken using Colaizzi's seven step approach to analysis. **Result:** Six themes emerged from the interviews: Losing a loved one, living with a family member experiencing paranoid thoughts, challenges in interpersonal relationships, living with hopeful expectations of recovery, the need for appropriate support from health professionals and the need for respite care for family members. **Conclusions:** The results of this study highlight the need to focus not only on the person experiencing a mental illness but also the family as a whole in caring for their family member with schizophrenia. Further research needs to identify the specific nursing interventions that are effective in helping Indonesian families in caring for a family member with schizophrenia.

Keyword: Family Caregiver, Experience, Schizophrenia, Phenomenologi

Introduction

In a population of 250 million Indonesian

people, 0.17 % has been diagnosed with schizophrenia¹. However, the bed capacity of the 48 mental health hospitals in

Indonesia is only around 7700². Consequently, the majority of these sufferers have little choice but to live in the community, either with their family or on the street.

Most patients who are discharged from hospital become entirely the family's responsibility, as the role of the family in caring for the patient is greatly emphasized in the context of community based care. Families, many of whom are lacking of knowledge in caring for an ill relative and have limited resources, are therefore forced to take responsibility for the sufferer's needs. This situation has created many problems for such families³. From my own experiences, as a psychiatric nurse and a member of an Indonesian family with a relative with schizophrenia, family members who are caring for patients with chronic mental illness undergo a number of psychosocial problems and financial concerns.

By ignoring this situation and reinforcing societal expectations, these families will remain overburdened with the responsibility for the sufferers' care, and mental health professionals will continue to be unable to address the need of the families and sufferers³. In Western countries, attention to this issue has been only evident since the early 1960's⁴. A number of studies have focused on the effects of chronic mental illness on the family, family attitude in caring for the patients, and family's coping strategies⁵. Some studies describe the burden of care⁶, and the objective and subjective burden of family caregivers⁷⁻⁸ and the correlation between the components of burden⁹. Another study looked at factors influencing the burden¹⁰. Recently, the view of caregiving burden has been broadened to involve the physical, psychological, social, and financial problems experienced by

families caring for a relative with a chronic or mental illness¹¹⁻¹².

Research evidences from eastern countries found that the subjective burden were correlated with quality of live of family caregivers of people with schizophrenia¹³, other studies found that the objective and subjective burden of family were influenced by the manifestation of the patopsychology of the patient's illness¹⁴, while other study conclude that the way the family perceived their budern were influenced by family functioning, health status and life satisfaction and social support¹⁵.

In Indonesia, only few published literature was found about family caregivers in the context of serious mental illness. A study by Rafiyah and Sutharangsee found that the caregivers caring for patients with schizophrenia experienced objective burden and subjective burden that involves emotional, physical health, social life, and financial status¹⁶. However, the study did not explore in-depth what such an experience is like. A deeper understanding of the experience of caring for relative with schizophrenia is important as understanding this phenomenon can inform the provision of quality appropriate family-centered care. This study attempts to explore the caregiver's perspective in an Indonesian family for a relative with schizophrenia.

Research Question

The research question that will be explored in this study is: What it is like being a caregiver in an Indonesian family for a relative with schizophrenia?

Methods

The phenomenological approach was selected as the most effective means by

which to achieve the aim of the study and provide answers to the key research question “What is it like being a caregiver for relative with schizophrenia? Methodologically, the research was guided by the work of Colaizzi¹⁷.

Participant Selection and Access

Purposeful sampling was used for the recruitment of participants. Nine Indonesia family caregivers, contacted through West Java Psychiatric Hospital. The family caregivers who are identified as meeting the criteria were visited at their home after contacting them by telephone or letter from the psychiatric hospital. Their involvement in caring for their relative with schizophrenia ranged from 6 months to 4 years. At the time of the study, all of the care recipients lived with the caregivers. The participant, who ranged in age from 35 to 70 years, were mostly parent caring for a son or daughter with schizophrenia. Only one participant cared for her sister. Most of participants were come from lower socioeconomic status. Two of them were come from middle class. Five participants were in paid employment, two participants had home industries and two participants were housewife.

Data collection and Analysis

Information was gathered through an audio-taped interview for about 45 – 60 minutes. Interviews conducted in the participants’ home. Each participants were interviewed twice. The first interview for information gathering. The Second interview for the purpose of providing an approach for both researcher and participant to seek clarification.

Information Analysis

Analysis of the participant transcripts utilized Colaizzi’s seven step approach. The narrative of participants from audio-taped

interviews was transcribed. Each participant’s description was read and re-read in order to obtain an overall sense of the participant’s experience, and then extracted significant statements. In the next step, the researcher formulated more general statements or meanings for each significant statement, and then organised the aggregate formalized meanings into clusters or themes. Before getting the fundamental structure/definition of the phenomena, the researcher wrote an exhaustive description of the phenomenon. The exhaustive description was validated with each participant.

Ethical consideration

In undertaking this project a number of ethical issues were addressed including: letter of approval, informed consent, anonymity, confidentiality, storage of data, level of risk, and right to withdraw without prejudice.

Results

The analysis of the participants’ transcripts using Colaizzi’s approach to analysis, identified six themes: Losing a loved one, become a victim of the patient’s emotion related paranoid, challenges in social relationships, acceptance and hope are starting point to rise up from the downturn, the need for appropriate support from health professional, and the need for respite care for family members.

1. Losing a love one

The majority of participants articulated that they felt loss of their love one. They felt no hope for the future of their ill relative. Participant 1 who cared for her son for 4 years described her experience: Look at my son, he always like that ...talking to himself. Smiling despite no one talking or joking. so what can I hope from him..... how can

he take care of me when I am old. No.... none I can hope from him. I lose him.

Another participant (participant 2) explain her grieving caused of lose: What should I say.... I lose her.... I lose her smile, her joy. She was an active girl before... but now... look at her... she just sit at the corner talking and smiling to her self. Caring for a relative with schizophrenia who never seems to get better makes most family caregivers experience frustration and hopelessness. I am alone in this situation and nothing can be done, because I have tried to heal her with a number of treatments ranging from western medicine to traditional healers. But no result. She always relapse.

In some cases where the family caregivers have lack of emotional and financial support, for example in a nuclear family that lives in an urban area such as Jakarta, Bandung and Surabaya, the feeling of frustration and hopelessness can fall into depression. In this cases, their relatives often leave the sufferer to live in the street.

2. Living with a family member experiencing paranoid thoughts

Being a caregiver for a relative with schizophrenia often experience emotional strain because of the paranoid of the ill relative, as stating by participant 4 as below: The most horrible moment in caring for my husband was when he began to relapse with paranoid thought I was suspected to have a special relationship with his brother. So, he was so angry to me. Every day he forced me to admit that I have a special relationship with his brother. I tried to refute his allegations, but only made him more angry to me.

Similarly, another participant (participant 6) told her experience being a victim of her daughter paranoid thought. I am preparing

food for her. When I served the food for her, she directly threw the plate and said Mom, you wanted to kill me, do you ? I was very sad to see my daughter in such circumstances.

The family caregivers also express fear for the wellbeing of their ill relatives and other family members related to paranoid thought of their ill relatives, particularly children. This feeling arises because of the unpredictability of their ill relative's emotions and behavior, and in some cases because of the ill relative's history of aggression. Participant 7 described his experience: I was being almost killed by my son who was wielding a knife. He was keeping told to me... you never love me... you are my enemi.. you are satan.... I kill you.

3. Challenges in interpersonal relationship

The families experience deprivation in social relationships because of their ill relative's uncontrolled behavior such as shouting or hitting a family member in public places, and the need for constant care. Participant 8 who cared for her son for 8 months described her experience: I really... really can't attend a wedding or other ceremonial invitations because he often does something that makes me feel embarrassed... such as shouting at me or hitting me.

Stigmatization is also a burden for the family caregivers. They believe that people will gossip about them because of their relative's mental illness. They also believe that relapse can be the result of stigmatization. This beleive were describe by participant 9 by saying:

After being discharged from hospital, if the community cannot accept him as he is, he will relapse... if they are always laughed at when he speaks or he is always left alone,

his illness will relapse. I feel embarrassed to my neighbor because we have relatives like him..... I feel embarrassed, especially when he shouted to our neighbour.

4. Living with hopeful expectations of recovery

Acceptance and hope are adaptational coping strategies that were used by the family caregivers. This coping makes them feel acceptable to their ill relative conditions. Participant 5 shared her experience by saying:

During the time of caring for my ill relative I always feel sad, disappointed, angry. It seems no hope. But when I accept the situation for what it is that's. Then, I was able to rise from the downturn. All negative feelings turned into hopeful. Another participant shared her feeling of their ill relative conditions I hope that at sometimes my ill relative will return to their former self. I have not given up, I still hope she can recover...Nevertheless, I no longer wish she would earn money or look after the family... I just hope she can look after herself because we will leave one day.

Similar to participant 5, participant 3 expressed her hope by stating: I hope she can recover from her illness. I will do everything for her. I believe Allah will help her to recover. While participant 8 stressed hope as a power to be strong in caring for her son by saying: I think, I have to seek for help and praying simultaneously. Because praying gives me hope. Hope that makes me strong to continue to care for my ill relative.

5. The need appropriate support from health professional

Furthermore, the difficulty in caring for the relative with schizophrenia can also arise from the lack of support from health

professionals and the lack of information and resources. Some respondents complain that they are not satisfied with the treatment they receive from professionals. They often feel upset because they feel the professionals directly or indirectly blame them for the cause of sufferer's relapse, and sometimes make judgmental statements.

Participant 5 shared her experience: They (health professionals) just blame us, they don't know what is really happening in our family...

Lack of support from professional and information may result from a lack of health education by the health professional as been complained by Participant 3: I did not know about my son's illness and how to cope in their daily lives because the health professionals had never give me this information. Families also complain that the community health professionals never pay attention to them, as complained by participant 1: No one of Community Health Center Staff has come to see our relative..." Similarly, participant 7 also complained: They never come to our home" and participant 9 expressed her feeling: I think, they don't care about our relative. In fact, they need information about their ill relatives as well as support from the health professional so that they can understand what really happens on their ill relatives and how to cope with the situation. As mentioned by participant 9: We need help.

We need help. We need doctor or nurse who care about us, not only to the patients. We need support from them... we need them to explain about what happens.. to our relatives.. not only give medicine.. like that.

6. The need for respite care for family members

Caregiving is demanding and it's normal to

need a break. This situation is highlighted by the experiences expressed by participant 1: I sometimes feel tired ... not only physically but also mentally ... sometimes I think perhaps there is someone who could replace my position even if only briefly to take care of my son. Similarly participant 4 stated: I often feel like suffering from this situation... it's really demanding. I need rest. While participant 6 shared different experience: I never felt depression care for my child. Fortunately there my sister who is willing to replace me by getting my daughter to stay at her home.

The families also experience an extreme condition as a caregiver. The families were forced to restrain their ill relative because their behavior disturbed and harmed other people. Participant 7 shared his experience:

At first, I still can be patient, I understand that he behave abnormal such as disturb and hit me or other because he is sick. But... when he always did it again and again..... I become anger and I hit him. You know I often feel embarrass because he often disturb our neighbor. I have ever restrained and put him in a room..... and knock the room door.

Therefore they need respite care, as stating by participant 3: Treated patients with schizophrenia? speechless What should I say, tired and bored ... I think as a caregiver we need day off, we need someone who can replace our role to miraculous time.

Discussion

A phenomenological study focuses on the exploration of a phenomena such as caring for relatives with schizophrenia¹⁸. The meanings constructed and articulated by participants concerning their experience of caring for their ill relatives assisted this

researcher to gain an insightful understanding of what it means to be someone who cares for relatives with schizophrenia.

Having family member suffer from schizophrenia impacted of feeling loss of love one. Grief, guilt, fear, and frustration were emotional responses experiencing by family caregiver cause of lose of love. In Indonesia, from a cultural perspective, children have responsibility to take care of their parents in old age. This norm has brought about grief among the parents of patients with chronic mental illness. Families, especially mothers, experience grief because they lose hope of their children becoming independent and taking care of them in old age. The grief reaction arises from watching the patients experience hallucinations, delusions and having difficulty in speaking and thinking over a long period of time.

Beside difficulty in speaking and thinking, some of the patients with schizophrenia also have paranoid thought¹⁹. This condition have impact on interpersonal relationships among family caregiver³. As founded in this study, the paranoid thoughts of the patients caused emotional strain among family's member. This situation added the burden for the caregiver. They felt hurt and frustrated.

Another bad experience of family caregiver in caring for their ill relative with schizophrenia in this study is being isolated from community as consequences of their ill relative's behaviour, such as shouting or hitting a family member in public places. This finding support previous study by Zahid and Ohaeri in which families reported the disruptive behaviour of their ill relative as the greatest burden beside economic burden and other¹³. This study also support another study by Rosenfarb,

Bellack and Azis that found sociocultural stress as consequences of their ill relative behaviour as the burden for the families⁵. The findings of this study is also support the finding of a study by Magliano et al. in which the families experience feeling embarrassed when they were in public places with the patients²⁰. Therefore they avoid talking about their ill relative with extended family and friends²¹. However, after joining family psychoeducation group intervention, the families could accept the patient's behaviour and help them in improving the patient's competence²⁰. So, it is important for the health professionals to provide psychoeducation for families who has relative with schizophrenia.

Hope is a crucial factor motivating the family caregivers to continue with the caregiving as found in this study. This findings support other previous study by Kelly & Gamble in which hope as the very important factor in the process of recovery of the patient with schizophrenia²². The families in this recent study have hope although sometimes they cannot explicitly explain about the grounds for the hope they hold for their ill relative. They usually have strong hope because they believe that God will not burden people more than is suitable for their capability. They also believe that if God is willing, their ill relative will recover. This positive attitude is also support the finding of Chang and Horrocks' study in which participants in their study spoke about the important of positive attitude in caring for patients with schizophrenia²¹. In this study, participants share that hope makes them never give up in caring for their ill relative.

Although the families have hope, they sometime also feel down when seeing their ill relative behaviour and do not know what to do. Lack of knowledge may result from a

lack of health education by the health professional. This finding is the reality about what really happen in mental health services in Indonesia that related to several factor such as the program of mental health is not include in the top priority program of health, lack of knowledge and motivation of the mental health staff and lack of budged for mental health program. The Indonesian Government spends only about 21 trillion rupiah of its national budget on health and only 9 billion rupiah is spent on mental health²³. The very small percentage allocated to mental health is in contrast to the recommendations of the WHO suggestion that every country should allocate at least 3% of its health budget on mental health services²⁴.

Caring for relative for a long period of time make the families feel tired and eventually exhausted. Therefore, they need help, they need someone to replace their role for a while. They need time for a while for refreshing. They need respite care. Respite care can be provided at home by a friend, other family member, volunteer or paid service or in a care setting, such as adult day care or residential facility. In Indonesia, there has no respite care in a care setting with paid service. However, the only respite care are from other family member or relatives.

This research has provided a description of the live experience of Indonesian living with a relative suffer from schizophrenia. This research calls for health professionals to gain a better understanding of being an Indonesian caregiver of an ill relative. As mentioned earlier, the caregivers of the schizophrenia experience psychosocial problems regarding the patient's abnormal behavior and the task of caring for them. They need for appropriate support from

health professional, and they need for respite care for family members.

Therefore, there is a need for health professionals to care for the mentally ill client in the context of a family-centered approach. This would include involving the whole family in providing care. Families could then work together as part of a team with the patient and mental health professionals²⁵⁻²⁶. Some effective interventions for the families include family education, family counseling and family support groups²⁵⁻²⁶. However, in doing this research it is clear that health professionals need to understand the importance of religion and culture when they are caring for patients and families.

Conclusion

This research has highlighted several themes that arise from Indonesian families experience in caring for relative with schizophrenia. This in turn demonstrates the lack of interest among the health professionals in the caregiver needs, and the lack of services provided for the family caregiver. An evaluation toward intervention that was implemented by health professionals in the past is greatly recommended. Research into the caregiving situation and factors surrounding this topic is warranted to give further insight into this problem, with the aim of improving mental health care.

References

1. Balitbangkes. Basic Health Research 2013. Depkes 2013 from <http://depkes.go.id/downloads/riskedas2013/Hasil%20Riskedas%202013.pdf>.
2. Irmansyah. 19 juta penduduk Indonesia gangguan jiwa. Haluan Post 2011. from http://www.harianhaluan.com/index.php?option=com_content&view=article&id=9385.
3. Suryani, S., Welch, A., & Cox, L. The Phenomena of Auditory Hallucination as Described by Indonesian People Living With Schizophrenia. Archives of Psychiatric Nursing. 2013; 27: 312-318.
4. Awad AG & Voruqanti LN. The burden of schizophrenia on caregivers: a review. Pharmacoeconomics. 2008; 26(2):149-62.
5. Rosenfarb, I.S., Bellack, A.S. and Azis, N. A Sociocultural Stress, Appraisal, and Coping Model of Subjective Burden and Family Attitudes Toward Patients With Schizophrenia. Journal of Abnormal Psychology. 2006; 115(1):157-165.
6. Caqueo-Urizar A & Gutierrez-Maldonado J. Burden of care in families of patients with schizophrenia. Quality of Life Research. 2006; 15: 719-724.
7. Jungbauer J, Wittmund B, Dietrich S and Angermeyer MC. The Disregarded Caregivers: Subjective Burden in Spouses of Schizophrenia Patients. Schizophrenia Bulletin. 2004; 30 (3): 665-675.
8. Singh1, Verma, Verma, Chaudhury. Subjective burden on spouses of schizophrenia patients. Industrial

- Psychiatry Journal. 2009; 18 (2): 97-100.
9. Perlick DA, Rosenheck RA, Kaczynski R, Swartz MS, Canive JM, & Lieberman, J.A. Components and Correlates of Family Burden in Schizophrenia. *Psychiatric services*. 2006; 57 (8): 1117-1125.
 10. Lowyck B, De Hert M, Peeters E, Gilis P & Peuskens J. Can we identify the factors influencing the burden on family members of patients with schizophrenia? *International Journal of Psychiatry in Clinical Practice* 2001, 5 : 89 – 96.
 11. World Federation of Mental Health (WFMH). *Caring for the caregiver: Why your mental health matters when you are caring for others*. Woodbridge VA: WFMH; 2010.
 12. Chan, S.W. Global Perspective of Burden of Family Caregivers for Persons With Schizophrenia. *Archives of Psychiatric Nursing*. 2011; 25 (5): 339-349.
 13. Zahid MA & Ohaeri JU. Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. *BMC Psychiatry* 2010; 10:71.
 14. Othman, Z. & Salleh, M.R. Burden of Care in Schizophrenia: Implication of psychopathology of the Illness. *Malaysia journal of psychiatry*. 2005; 13 (2): 34-40.
 15. Chien WT, Chan SW, & Morrissey J. The perceived burden among Chinese family caregivers of people with schizophrenia. *Journal of Clinical Nursing*. 2007; 16:1151-1161.
 16. Rafiyah I & Sutharangsee W. Review: Burden on Family Caregivers Caring for Patients with Schizophrenia and Its Related Factors. *Nurse Media Journal of Nursing*. 2011; 1(1): 29-41.
 17. Colaizzi, P. *Reflection and Research in Psychology: A Phenomenological Study of Learning*. USA: Kendall/Hunt Publishing Company; 1973.
 18. Giorgi, A. *Phenomenology in J.A. Smith (Eds.). Qualitative psychology: A practical guide to research method (pp.26-51)*. London: Sage publications; 2008.
 19. Freeman D & Garety P. Helping patients with paranoid and suspicious thoughts: a cognitive-behavioural approach. *Advances in Psychiatric Treatment*. 2006; 12: 404-415.
 20. Magliano L, Fiorillo A, Malangone C, De Rosa C, & Maj M. Patient Functioning and Family Burden in a Controlled, Real-World Trial of Family. *Psychiatric service*. 2006; 57 (12): 1784-1791.
 21. Chang KH & Horrocks S. Lived experience of family caregivers of mentally ill relatives. *Journal of Advanced Nursing*. 2006; 53(4), 435-443.
 22. Kelly, M & Gamble C. Exploring the concept of recovery in schizophrenia. *Journal of Psychiatric and Mental Health Nursing*. 2005; 12: 245-251.

23. Victoria, W. Menkes Janjikan Anggaran Kesehatan Jiwa Naik. Rakyat Merdeka Online 2002. Retrieved August 10, 2012 from <http://www.rakyatmerdeka.co.id/news/2010/01/27/87137/>.
24. Saxena S, Thornicroft G, Knapp M & Whiteford H. Global Mental Health 2: Resources for mental health: scarcity, inequity, and inefficiency. *The lancet*. 2007; 370: 878–89.
25. Chan S, Yip B, Tso S, Cheng BS, & Tam W. (2009). Evaluation of a psychoeducation program for Chinese clients with schizophrenia and their family caregivers. *Patient Education and Counseling*. 2009; 75: 67-76.
26. Nasr, T & Kausar, R. Psychoeducation and the family burden in schizophrenia: a randomized controlled trial. *Annals of General Psychiatry*. 2009; 8 (17): 1-6.

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