



## Emotional reactions and coping strategies of carers of people with serious mental illnesses: A focus group study<sup>☆</sup>



Herni Susanti<sup>a,\*</sup>, Karina Lovell<sup>b</sup>, Hilary Mairs<sup>b</sup>

<sup>a</sup> Faculty of Nursing, Universitas Indonesia, Depok, West Java, Indonesia

<sup>b</sup> Division of Nursing, Midwifery, and Social Work; School of Health Sciences, Faculty of Biology, Medicine and Health, University of Manchester, UK

Received 13 November 2018; accepted 17 April 2019

Available online 28 June 2019

### KEYWORDS

Serious mental illness;  
Carer;  
Service user;  
Coping;  
Focus groups

### Abstract

**Objective:** This study aimed to explore the perception of caring for individuals with serious mental illnesses from the perspectives of carers and service users.

**Method:** This was a qualitative research employing nine focus groups. A total of 46 participants involved in the study, consisted of seven groups of carers ( $n = 33$ ) and two groups of service users ( $n = 13$ ). The entire participants were recruited from two government mental health hospitals in Indonesia. The data were analysed by using framework analysis.

**Results:** Both service user and carer participants perceived that caring for individuals with serious mental illnesses with regard to emotional reactions and coping strategies in undertaking caregiving role.

**Conclusion:** The study suggests that taking care of individuals with serious mental illnesses was not just a burden but that it could also be rewarding. In addition, the cultural beliefs have guided the carers for seeking help from traditional healers instead of medical professionals especially in the initial phase of the relatives' illness. The finding recommends to an application of culturally-based approaches in order to deliver effective professional support for the carers.

© 2019 Elsevier España, S.L.U. All rights reserved.

<sup>☆</sup> Peer-review under responsibility of the scientific committee of the Second International Nursing Scholar Congress (INSC 2018) of Faculty of Nursing, Universitas Indonesia. Full-text and the content of it is under responsibility of authors of the article.

\* Corresponding author.

E-mail address: [herni-s@ui.ac.id](mailto:herni-s@ui.ac.id) (H. Susanti).

## Introduction

Carers of people with serious mental illnesses are those who deliver care to a family member with a long-term mental disorder including schizophrenia, schizoaffective disorder, bipolar disorders and major depressive disorder.<sup>1,2</sup> These carers often expressed problems associated with their caregiving roles such as disruption of social and leisure activities, as well as issues surrounding finance, health and well-being. Despite their own burden, carers are considered to be responsible for their relatives' wellbeing. Carers are expected to play important roles in maintaining the mental health of service users, and providing first treatment during acute periods. Carers are also essential in providing information to health workers about the symptoms experienced by service users as well as their needs of care.

Clearly, caring for a relative with serious mental illnesses can be taxing. Understanding carers' and service users' perceptions surrounding the caregiving can give insight of how the carers look after their relatives. However, studies exploring the caregiving are mainly sourced from carers' perspective.<sup>3</sup> Limited investigations involved the ill family members, as the caregiving receivers, to voice their views and expectations of the care given. This study aimed to answer a question: what do carers and service users think about caring for people with serious mental illnesses in Indonesia? Indonesia is a country where mental health problems are increasing. In 2013, there are 14 million people or as many as 6% of the total population experienced mental health problems which had an impact on low productivity and increased burden in carers up to 1.2%.<sup>3</sup>

## Method

This was a descriptive qualitative study involved carers and service users in Indonesia. Meaningful investigations in mental health field can be achieved through the application of qualitative research which requires subjective responses stemming from the perspectives of relevant people.<sup>4</sup>

Convenience sampling was adopted because the main researcher (i.e. the first author) was dependent on referrals from gatekeepers to recruit. Nevertheless, some systematic activities were involved by referring to the ethics approvals in reaching and recruiting the convenient sample such as identified potential participants based on the established criteria and provided them information about the research adequately.<sup>5</sup>

The inclusion criteria for carer and service user participants consecutively were adult carers aged 18 years who have a relative admitted to one of two mental health hospitals in the capital city of the country (i.e. Soeharto Heerdjan or Duren Sawit hospitals); and adult service users aged 18 years and over who were inpatients registered at the two hospitals for a serious mental illness (i.e. medically documented as suffering from schizophrenia, schizoaffective disorders, bipolar disorders, or chronic depression).

The study obtained approval from two ethical committees: the University of Manchester and the Indonesian Nursing Ethics Committee. The approval from the University was related to the Indonesian Nursing Ethics Committee so that approval to conduct research in the country could be

issued. This was followed by obtaining approval from two mental health hospitals where the studies were conducted.

A target of 38–48 carers and service users (i.e. for 6 focus groups) was expected to elicit sufficient data for data saturation to occur.<sup>6</sup> In order to recruit service users, the main researcher talked to a number of managers of inpatient wards to generate a list of potential service users. The potential service users were then invited to a meeting to discuss the study. Carers were recruited in a series of stages because access to them could only be initiated after the service user consented their caregiver for participation. Having had invited the potential service users, they were asked, if they had a relative, to consent for their relative to be approached to take part as a carer participant. The consented relatives were then contacted to receive an information sheet about the carer part of the study. After all, both potential service user and carer participants were given 48 h to decide whether to participate or not. Those who agreed to participate were asked to sign a consent form and invited to focus group discussions which were held separately for both samples.

The study employed focus groups as the method of data collection. A discussion schedule was developed from the literature review to identify common issues surrounding the caregiving of people with serious mental illnesses. Subsequently, the researchers phrased a number of questions and sequenced them from general to specific questions.<sup>6</sup>

For every focus group, the main researcher undertook the role of moderator, a person who has an authority to direct the session and keep it flowing.<sup>6</sup> All conversations were digitally recorded. In addition, the researcher worked with a co-moderator to take notes and check the video recording during every meeting. The data were analysed by using framework analysis.

## Results

Nine focus groups of between three to nine participants were conducted with a total of 46 participants; two groups with service users ( $n=13$ ) and seven groups with carers ( $n=33$ ). All sessions were conducted for about 40 min.

The average age of service user participants was 39 years (range 27–60). All service user participants were diagnosed with schizophrenia according to their medical records. Of the 13 service users, only two who had relatives participated in the carer focus groups.

The average age of carer participants was 50 years (range 25–69). Most of the carers were parents ( $n=23$ ), followed by siblings ( $n=5$ ), children ( $n=2$ ), spouse ( $n=1$ ), uncle ( $n=1$ ), and sister in law ( $n=1$ ). The carer participants were mostly female (20:13). The average duration of illness of their ill relatives was 8.5 years

Two main themes emerged from the focus groups, as described as follows:

### Theme 1: emotional reactions associated with caregiving

The carer participants exposed a number of negative emotions related to caregiving. For example, the feelings of humiliation and being stigmatised were expressed along with

grief. This evident in the case of carers who were sad when describing how their relatives were humiliated because of suffering from a mental health problem:

“People do not want my children [service users] to live in the neighbourhood. One day, my daughter was unstable and hit someone. Then she was dragged on the street by the people...she was bleeding badly... Bleeding on her knees...” “[showing knee and crying]”. (29A, focus group 5)

In addition, some parent carers maintained that the distress was primarily because their adult children were unemployed. Unemployment caused significant difficulties for the parents who assisted the service users financially, by means of contributing to their expenses for meals, groceries, clothes and transportation to visit mental health services. Parallel with the carer participants, the service users in the study also realised that meeting the caregiving costs was very distressing, as reflected in the following quote:

“It is hard, in terms of finance and other things related. My brother has to help me [financially]. . . So if it is said to be stressful. . .yes, it is very stressful for him. . .especially when he has to expend money for my needs. . .for the cost of medication and treatment and my daily life. . .the costs for everything. . .”. (9B, focus group 7)

Some of the carers stated that their caregiving tasks were not only physically tiring (e.g. for staying awake when their relatives were unable to sleep for days); but also psychologically draining (e.g. persistent and enduring stress resulting from caregiving roles). One carer expected her son to recover, or if it was not possible she accepted the service user to die; thus it would reduce her exhaustion in caring for a family member with mental illness as shown in the following quotation:

“I plead God in every prayer, ‘O... Allah, if You can heal him. . .please give him the healing. . .if he can’t be cured, just take him. I am so tired!’”. (32A, focus group 5)

Finally, frustration was reported by the carers in regard to their relatives’ inability to control symptoms which reflected a decrease in or loss of normal functions (so-called as negative symptoms). The negative symptoms observed in family members included a lack of interest to carry out self-care and/or household activities. One carer was shouting when revealing the amount of time that her husband spent for caring for his ill sibling:

“She [service user] is my husband’s sister. He is looking after a depressed person. She does nothing...does not want to eat...does not want to do households... I feel frustrated as my husband is only taking care of this sister. Like no one else can take care of her. Then he does not care about his own wife. His attention is dedicated only to his sister”. (31A, focus group 5)

Some positive emotional reactions associated with caregiving were also revealed. To illustrate, gratefulness was obvious in carer focus groups, even though it was not apparent in service user groups. Some of the carers were relieved diagnosis was established:

“So now I’m very grateful because I already know [the illness], and we can be tolerant to him. Eventually it is true that my son has a mental disorder. Before now, there were many opinions from lefts and rights, such as that he might be possessed and so on. (5A, focus group 2)

Despite the distress and frustration elicited by carers they all expressed compassion or sympathy for their ill relatives:

“I feel sympathy on her and then we are doing what we can do. We are trying to give what she wants. . . What she needs”.... (11A, focus group 2)

The sense of being cared for was also evident in service user groups even though it was less prevalent than in carer groups (i.e. only expressed by four of the 13 service users). The four service users believed that their carers had done the best by facilitating them to be treated in the inpatient care as illustrated in the following conversation:

“When my emotions were very high, I could even hurt my nieces and nephews. Therefore, I was finally brought into this hospital. I knew my brother actually did not want to put me here. But what could he do? I think my brother really cares about me. . .he is very sympathetic towards me. . .as the youngest sister. . .having stress problems like this”.... (9B, focus group 8)

## Theme 2: coping strategies in undertaking caregiving role

The focus groups uncovered data of how Indonesian carers coped with stressful events stemming from the relatives’ illness, including detecting early signs of the illness, managing the symptoms and isolating service users from the society. The findings were mainly revealed in the carer focus groups. To illustrate, most of the carer participants spoke about their journey in discovering their relatives’ mental health problem. The carers’ commitment to help service users in the early stages of mental health problems is shown in the following conversation:

27 A: “Yeah...I brought my son to a healer...then I followed what the healer said. He said, ‘Bring him back here...bring 1.5 million rupiahs as well. Also bring a special chicken...’”

28 A: yeah the same with me...I brought him to a healer. Then he stayed in the healer’s house for 2 days. But then, the healer said, ‘You have sold your house for treating him to many healers, haven’t you?’ I replied, ‘Yes, you’re right’. The healer then said, ‘This is too late Ma’am. This is like a rusty nail. It’s better to bring him to a hospital...go to psychiatrists’. (Focus group 5)

The above conversation clearly reflected the carers’ endeavours for supporting their ill relatives. Such support continued after they had accepted a psychiatric diagnosis. Some of the carers disclosed their efforts to assist their relatives in controlling the symptoms, especially by following the professionals’ suggestions related to caregiving.

Nevertheless, other carers in the focus groups exposed diverse responses in that labelling relatives’ problem as a

mental disorder could also be disadvantageous for the service users. For example, a mother disclosed that her adult son had been isolated by placing him in 'a special space' of the house.

"I prepared a special room for my [ill] son, because if he was outside the room, he would be furious... Yes, a room with a WC and a bed... My brother said, "Please, sister...don't bring your son anywhere else. Even if you sell your house for his treatment, he will not recover". Therefore, I made a special room for my son. Then he has been in the room for five years, but finally he is now here [in a mental health hospital] because a staff from the community health centre came to my house and told me to hospitalise my son". (32A, focus group 5)

In the following conversation it was found that the decision of hospitalisation did not change the carer's intention to terminate the seclusion.

## Discussions

### Emotional reactions associated with caregiving

The carer reported various emotional reactions when caring for relatives with serious mental illness including feelings of shame, stigmatised, sadness, distressed, frustration, tiredness, worried, confusion, resentment, anger, gratefulness and compassion for the service users. These reactions have also been found in previous investigations that explored caregiving experiences in mental health fields.<sup>7-11</sup> Clearly, most participants discussed negative emotional responses even though a few positive responses were also elicited.

In regard to frustration, this feeling was reported by the carers associated with negative symptoms. This finding is similar to the data from previous studies which considered negative symptoms to be more burdensome than other symptoms like hallucination and delusion (so-called as positive symptoms).<sup>12-14</sup>

As indicated previously, some positive emotional reactions associated with caregiving were also revealed. For example, gratefulness was obvious in carer focus groups. These carers had relied on the common cultural belief in that a mental health problem was caused by a supernatural power therefore they sought help from traditional healers. However, after some months or years, the carers found that the traditional healers' help was not really satisfying as they still had remaining questions about the problems that their relative was experiencing. Having a definitive diagnosis of mental disorder was comforting, as the carers no longer had to live under a cloud of confusion of what was wrong with service users which had continued for a long period of time.<sup>7</sup>

### Coping strategies in undertaking caregiving role

Most of the carer participants spoke about their journey in discovering their relatives' mental health problem. The described endeavours were not unusual in Indonesian culture which is not reliant upon the medical model for confirming the underlying nature of mental health problems, especially in the first episode of occurrence.<sup>15</sup> The medical model emphasises that mental health problems have an

organic or physical cause such as chemical imbalance or abnormality in a part of the brain, the problems are then labelled by a doctor on the basis of specific behaviours-so-called as symptoms-which are reported by families or observed by health professional; and eventually the treatments are designed by the professionals to deal with the health impairment.<sup>16,17</sup> Alternatively, the carer participants had relied on the common cultural beliefs in many non-industrialised countries; emphasising that mental health problems are caused by demons, witchcrafts, or spirits; therefore, they sought help from traditional healers.<sup>15,18</sup> The perception that mental health problems is influenced by a supernatural power has led to supportive attitudes of Indonesian carers (e.g. not blaming service users for the presence of problems and having strong willingness to help through the traditional healers).<sup>15</sup>

Nevertheless, other carers in the focus groups exposed diverse responses, amplified the evidence that labelling relatives' problem as a mental disorder could also be disadvantageous for the service users.<sup>8,11</sup> Once the relatives were diagnosed with a mental health disorder which exhibited negative symptoms (e.g. deprivation of motivation for daily activities and social contacts), their carers might limit their activities and interactions with other people.<sup>11</sup>

In the current focus groups, some carers believed that people diagnosed with a mental health disorder were violent thus restricting them for social contacts was deemed necessary to anticipate their unexpected behaviours, such as throwing things or becoming aggressive towards surrounding people. In the following conversation it was found that the decision of hospitalisation did not change the carer's intention to terminate the seclusion. The carer affirmed that while the service user was being treated in the inpatient, refurbishment of the 'special room' was made for re-occupation. It is argued that the health professionals applied the paternalistic model in making the decision concerning the service user's treatment. Within this model, professionals are the main decision makers who articulate what is best for service users, and carers' opinions related to treatment for their ill relatives are often overlooked.<sup>19</sup>

### The strengths of the study

The strength of this study is related to the chosen data collection method. The study adopted focus groups with carers and service users which have elicited rich information about carer needs. Conversations about mental health in other circumstances such as individual interviews might be difficult because of stigma or giving no opportunity to the carers and service users to compare and share feelings about caregiving.<sup>20</sup>

### The limitations of the study

The carers in the study were not a representative sample of relatives of people with serious mental illness in Indonesia. The carer participants were predominantly female, typically mothers or sisters of the ill persons. Understandably, female carers are recognised to be more responsible and motivated in activities relating to caregiving.<sup>21,22</sup>

## Conclusion

In general, the experiences revealed were consistent with the findings of other investigations, suggesting that taking care of individuals with serious mental illnesses was not just a burden but that it could also be rewarding. In the current study some burdensome feelings like tiredness, frustration and distress which understandably emerged when caring for people with enduring illnesses were exposed together with some contrasting emotions such as gratefulness and compassion. Likewise, while some coping strategies which seemed to be disadvantageous to service users were identified (e.g. protecting them from social life); more endeavours were uncovered (e.g. detecting the illness and managing the symptoms) suggesting that the carers were relatively attentive to their ill relatives.

The study also has uncovered essential facts about the carers' cultural values that have influenced their efforts in dealing with caring roles. The cultural beliefs have guided the carers for seeking help from traditional healers instead of medical professionals especially in the initial phase of the relatives' illness. At the end, this finding recommends to an application of culturally-based approaches in order to deliver effective professional support for the carers. The approach opens for negotiation, instead of imposing, between traditional beliefs and biomedical practices. The approach also regards the carers as the active rather than passive recipients of the professional support, allowing them to employ non-hazardous traditional beliefs in caring for their relatives.

## Conflict of interests

The authors declare no conflict of interest.

## References

1. Cleary M, Freeman A, Hunt G, Walter G. What patients and carers want to know: an exploration of information and resource needs in adult mental health services. *Aust NZ J Psychiatry*. 2005;39:507–13, <http://dx.doi.org/10.1080/j.1440-1614.2005.01611.x>.
2. Janardhana N, Raghunandan S, Naidu D, Saraswathi L, Seshan V. Care giving of people with severe mental illness: an Indian experience. *Indian J Psychol Med*. 2015;37:184, <http://dx.doi.org/10.4103/0253-7176.155619>.
3. Susanti H, Lovell K, Mairs H. What does the literature suggest about what carers need from mental health services for their own wellbeing? A systematic review. *Enferm Clín*. 2018;28:102–11, [http://dx.doi.org/10.1016/S1130-8621\(18\)30047-0](http://dx.doi.org/10.1016/S1130-8621(18)30047-0).
4. Flick U. *Managing quality in qualitative research*. London: Sage Publication Ltd; 2008.
5. Koerber A, McMichael L. Qualitative sampling methods. *J Bus Tech Commun*. 2008;22:454–73, <http://dx.doi.org/10.1177/1050651908320362>.
6. Krueger R, Casey M. *Focus groups*. Thousand Oaks, CA: Sage Publications; 2015.
7. Szmukler G, Burgess P, Herrman H, Bloch S, Benson A, Colusa S. Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. *Soc Psychiatry Psychiatr Epidemiol*. 1996;31:137–48, <http://dx.doi.org/10.1007/BF00785760>.
8. Karp D, Tanarugsachock V. Mental illness caregiving, and emotion management. *Qual Health Res*. 2000;10:6–25, <http://dx.doi.org/10.1177/104973200129118219>.
9. Veltman A, Cameron J, Stewart D. The experience of providing care to relatives with chronic mental illness. *J Nerv Ment Dis*. 2002;190:108–14.
10. Schulze B, Angermeyer M. Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Soc Sci Med*. 2003;56:299–312, [http://dx.doi.org/10.1016/S0277-9536\(02\)00028-X](http://dx.doi.org/10.1016/S0277-9536(02)00028-X).
11. Rose L, Mallinson R, Gerson L. Mastery burden, and areas of concern among family caregivers of mentally ill persons. *Arch Psychiatr Nurs*. 2006;20:41–51, <http://dx.doi.org/10.1016/j.apnu.2005.08.009>.
12. Provencher H, Mueser K. Positive and negative symptom behaviors and caregiver burden in the relatives of persons with schizophrenia. *Schizophr Res*. 1997;26:71–80, [http://dx.doi.org/10.1016/S0920-9964\(97\)00043-1](http://dx.doi.org/10.1016/S0920-9964(97)00043-1).
13. Tucker C, Barker A, Gregoire A. Living with schizophrenia: caring for a person with a severe mental illness. *Soc Psychiatry Psychiatr Epidemiol*. 1998;33:305–9, <http://dx.doi.org/10.1007/s001270050059>.
14. Barrowclough C, Haddock G, Wykes T, Beardmore R, Conrod P, Craig T, et al. Integrated motivational interviewing and cognitive behavioural therapy for people with psychosis and comorbid substance misuse: randomised controlled trial. *BMJ*. 2010;341:c6325, <http://dx.doi.org/10.1136/bmj.c6325>.
15. Kurihara T, Kato M, Tsukahara T, Takano Y, Reverger R. The low prevalence of high levels of expressed emotion in Bali. *Psychiatry Res*. 2000;94:229–38, [http://dx.doi.org/10.1016/S0165-1781\(00\)00143-8](http://dx.doi.org/10.1016/S0165-1781(00)00143-8).
16. Klerman G. Mental illness, the medical model, and psychiatry. *J Med Philos*. 1977;2:220–43, <http://dx.doi.org/10.1093/jmp/2.3.220>.
17. Elkins D. *Humanistic psychology: a clinical manifesto. A critique of clinical psychology and the need for progressive alternative*. Colorado: University of the Rockies Press; 2009.
18. Mavundla T, Toth F, Mphelane M. Caregiver experience in mental illness: a perspective from a rural community in South Africa. *Int J Ment Health Nurs*. 2009;18:357–67, <http://dx.doi.org/10.1111/j.1447-0349.2009.00624.x>.
19. Llewellyn-Thomas H. Patients' health-care decision making. *Med Decis Making*. 1995;15:101–6, <http://dx.doi.org/10.1177/0272989X9501500201>.
20. McAuliffe D, Andriske L, Moller E, O'Brien M, Breslin P, Hickey P. 'Who cares?' An exploratory study of carer needs in adult mental health. *Aust e-J Adv Mental Health*. 2009;8:57–68, <http://dx.doi.org/10.5172/jamh.8.1.57>.
21. Cognitive behavioural therapy for psychosis: developing family intervention for schizophrenia in Egypt [unpublished thesis]. Manchester: University of Manchester.
22. Mizuno E, Takataya K, Kamizawa N, Sakai I, Yamazaki Y. Female families' experiences of caring for persons with schizophrenia. *Arch Psychiatr Nurs*. 2013;27:72–7, <http://dx.doi.org/10.1016/j.apnu.2012.10.007>.