



FAMILY CAREGIVER'S EXPERIENCES USING COMMUNITY MENTAL HEALTH SERVICES IN MALAYSIA

(Pengalaman Penjaga Keluarga menggunakan Perkhidmatan Kesihatan Mental Komuniti di Malaysia)

Mohamad, M. S., Sheau Tsuey Chong, Hoesni, S. M., Subhi, N., Sarnon, N. & Nen, S.

Abstract

Many studies of family caregiving have found mixed findings in evaluating the effectiveness of community services in reducing family caregiver stress. In addition, the study also showed that some of the caregiver has limited experience in obtaining care. The purpose of this article was to describe the experience of the use of community mental health services, including benefits and barriers, by family caregivers of schizophrenic patients in Malaysia. Community mental health services included assistance with caregiving and educational as well as emotional support by community mental health professionals. In this qualitative descriptive study, a purposive sample of 24 family caregivers was interviewed. Semi-structured interview technique was used to explore the caregivers' experiences with community mental health services. Transcribed data were analysed using qualitative framework-analysis techniques. Results indicated that family caregivers received benefits of personal respite, sense of community, financial and emotional supports as well as gained practical knowledge and believed that their family also benefited from the community services used. Barriers to service use included lack of attention, accessibility issues and concerns over quality. All the findings in this study provide direction for mental health workers in targeting interventions that will meet the caregivers' needs and desires.

Keywords: Family, Caregivers, Community Services, Mental Health

Abstrak

Banyak kajian tentang penjagaan keluarga telah menemui pelbagai keputusan tentang penilaian keberkesanan perkhidmatan komuniti yang dapat mengurangkan stress penjagaan. Selain itu, dapatan kajian juga menunjukkan bahawa ramai daripada penjaga mempunyai pengalaman yang terhad dalam mendapatkan perkhidmatan penjagaan. Tujuan kajian ini adalah untuk menerangkan pengalaman penggunaan perkhidmatan kesihatan mental komuniti yang memberi faedah dan halangan kepada penjaga yang mempunyai pesakit schizophrenia di Malaysia. Perkhidmatan kesihatan mental komuniti melibatkan bantuan penjagaan dan pendidikan serta sokongan emosi daripada golongan profesional dalam kesihatan mental komuniti. Dalam kajian kualitatif deskriptif ini, satu sampel bertujuan yang terdiri daripada 24 keluarga telah ditemu bual pada Februari 2008 hingga Jun 2008 di Ipoh, Perak dan Pendang, Kedah. Kaedah temu bual semi-struktur telah digunakan untuk meneroka pengalaman penjaga dengan perkhidmatan kesihatan mental komuniti. Data transkripsi telah di analisis menggunakan teknik analisis-kerangka kualitatif. Hasil kajian mendapati bahawa penjaga keluarga menerima faedah-faedah seperti masa untuk diri sendiri, perasaan bermasyarakat, sokongan kewangan dan emosi serta mendapat pengetahuan yang praktikal dan percaya bahawa ahli keluarga mereka juga mendapat faedah daripada perkhidmatan yang digunakan. Halangan-halangan dalam perkhidmatan kesihatan mental komuniti termasuklah kurang perhatian, isu-isu aksesibiliti dan perkara yang berkaitan dengan kualiti. Semua hasil kajian dapat memberi arah tujuan kepada pekerja kesihatan mental komuniti dalam memfokuskan intervensi yang akan memenuhi keperluan dan kehendak penjaga.

INTRODUCTION

Previous studies of family caregiving reported that some of the family caregivers can be physically demanding and psychologically stressful especially for those families who assume care for a relative with schizophrenia. In 2003, the Malaysia Ministry of Health introduced the National Mental Health Registry (NHMR), specifically for the monitoring schizophrenic patients (Aziz et al. 2008). The NHMR published its schizophrenia Report 2003-2005 which gives a glimpse on the status of care for schizophrenia patients. The report showed there were 7, 351 cases registered nationwide based on the primary data from the Ministry of Health and University Hospitals (Ministry of Health 2008). Many patients diagnosed with schizophrenia return to live with their family, at least temporarily, after they left hospital (Malaysian Psychiatric Association 2010).

Many researchers in Western countries noted that family caregivers not only provide the basic needs of care like long-term assistance of housing and financial aid, but they also serve as agents of the rehabilitation process in the community mental health services (Hsio & Van Riper 2010; Dixon et al. 2001; Marsh & Johnson 1997; Lefley 1996). They found that the mental health professionals made a sustained attempt to develop a partnership with service users including mental health service users and their families (Webb 2008; Barnes et al. 2000; Levin 2004; Carpenter et al. 2004; Fadden et al. 2005; Tew et al. 2004). However, many studies in Western cultures found that the family caregivers were vulnerable in providing the ongoing care and support demanded by their family members. These caregivers also struggled to manage unexpected situations, especially in societies that provide limited resources for mental health (Roick et al. 2006; Doornbos 2002; Wooff et al 2003; Magliano et al. 2005; Lefley 1998; Marsh 1999). The caregiver's roles become more challenging when the policy concerning deinstitutionalisation was introduced to promote community care.

Since the year of 2000, there has been a decline in the number of mental health service users in psychiatric hospitals throughout Malaysia due to the deinstitutionalisation policy. One of the salient impacts of this policy and the recent development in the community mental health services is that an increasing number of families are now involved in taking care of the mentally ill patients. A few studies were conducted in Malaysia about family caregivers for people with severe mental illness. For instance, Chang and Horrocks (2006) reported that Chinese family caregivers were 'forced' to accept the caregiving role of their mentally ill patients. However, their study does not reflect the Malaysian population as a whole because there are three main ethnic groups in Malaysia, namely, the Malays, Chinese and Indians. Furthermore, there was another study done by Zahiruddin and Salleh (2005), which was conducted in semi-rural areas on the burden borne by family caregivers for caring for relatives diagnosed with schizophrenia. However, their study also focused only to Malay family caregivers. Therefore, lack of literature about family caregiving in Malaysia. Chen & Greenberg (2004) argued that the experiences of family caregiver do not necessarily have to be negative. There are also positive aspects of family caregiving (Schwartz & Gidron 2002; Schene et al. 1998; Tessler & Gamache 2000). Hence, the current study is indeed very much needed in exploring both aspects of caregiving especially in Eastern countries.

Since the promotion of the community care, many families are taking care of their relatives in Malaysia. However, the lack of knowledge and lower mental health literacy plus the devotion to the traditional belief systems pose challenges to family caregivers, mental health patients and service providers. Furthermore, the mental health issue is more alarming because of the lack of community mental health facilities, especially in the rural areas, whilst the number of family caregivers looking after their relatives is increasing. Therefore, this article aims to describe the family caregivers' experiences with use of community services in Malaysian context. Specifically, it was to describe the benefits and barriers of the community mental health services.

METHODOLOGY

A qualitative, descriptive research method as suggested by Flick (2006) was undertaken to analyse the family caregiver's experiences with the use of community mental health services. Participants were recruited from two community clinics in Ipoh, Perak and Pendang, Kedah in February 2008 until June 2008. A formal ethical approval and administrative clearance was obtained from the National Medical Research Register, Ministry of Health of Malaysia. A written informed consent was obtained from each participant. Subsequently, the participants were given a choice to select the interview site based on their convenience whether in their homes or in the community clinics. The interview would take approximately 45 minutes and it would be audio-taped.

a. Sample

Twenty-four family caregivers volunteered to participate in the study. Two thirds were Malays, with six Chinese and two Indians. Most of the Malays dwell in the rural area and all but one of the Chinese live in the urban area. The caregivers were recruited equally from both the urban and rural areas. More female (14) than male (10) caregivers were interviewed. Most were parents with two thirds being mothers. An equal number of husbands and wives were recruited in this study. There were five siblings, two brothers and three sisters of schizophrenic patients. Most of the caregivers were aged 50 years old and above. Only one of the caregivers was younger, below 40 years old.

These participants had been providing care for from one year to more than 20 years. The average of caring duration was 12 years. Most of the caregivers had used the community mental health services for almost five years. This was to be expected, since participants had been recruited from the community clinics that offer the community mental health services. The most frequent service used was adult day care in the psychosocial rehabilitation centre.

b. Data Collection

This study used a semi-structured interview because it follows a less rigid format with open-ended questions to elicit more qualitative information. Barriball (1994) suggested that a semi-structured interview is an efficient technique to obtain information from people who have limited time available for an interview and allows the researcher to make sure the "key issues" are covered. The researcher conducted semi-structured interviews with the main carers. The main carer was defined as the family member who spends most of the time with the relative and it must be proven by the relative as being one without whom the relative would be able to maintain their position living in the community.

The semi-structured interview enables exploration of the use of services from the carers' perspectives in respect of their caring roles to people with mental illness in their home

setting. The focus of each interview was to learn the caregiver's experience about what the services did for them and what kept them from using services. The initial question of all participants was what community mental health services do you use to help you with the caregiving. Then, the researcher invited the caregivers to describe the services they had used and they were asked to explain what was their opinion towards the use of services. Follow-up questions were used to encourage participants to explain more fully or to clarify meanings of participant's responses. The interviews concluded with the question about benefits and barriers of the use of community mental health services. Data collection stopped when reached the point of data saturation, which no new information about the use of community mental health services could be identified.

c. Data Analysis

Each of the interviews was transcribed. The researcher reviewed the transcripts while listening to tapes and conducting the transcription to make sure that the interview content was complete. A second reading of the transcripts was then completed to obtain a general impression of the caregivers' experiences of services use, particularly to the benefits and barriers experienced by the caregivers. The data analysis was conducted using the Nvivo to see the free nodes emerged. Later, all emerging nodes were clustered under the tree nodes. The framework analysis suggested by Ritchie et al. (2003) was applied. There were five stages of framework analysis:

1. Familiarisation with data (becoming thoroughly immersed in the material collected)
2. Indexing data (labelling key issues that emerge across a set of data)
3. Devising a series of thematic charts (allowing the full pattern across a set of data to be explored and reviewed)
4. Mapping and interpreting data (looking for associations, providing explanations, highlighting key characteristics and ideas)
5. Developing a thematic framework (identifying key issues from data)

The same framework was used to map the themes and sub-themes into different groups such as urban versus rural and Malay versus non-Malay to see the similarities and differences between the caregiver's answers. Later, the main theme of caregiving experiences was further examined using all those frameworks to identify categories and patterns in caregivers' responses. Verbatim quotes from study participants were selected to illustrate the identified themes and categories. The frequency of themes emerged was also recorded to see which issue or idea was commonly discussed by caregivers.

FINDINGS

Seven major categories of benefits of service use and three categories of barriers to service use were identified from the data analysis. A description of those categories with supporting data follows.

a) Benefits of Using Mental Health Services

The family caregivers who accept the medical treatment for patients identified several benefits of using the community mental health services. These benefits include the feeling of support through the home-based treatment, gaining information and practical knowledge, experiencing community support, gaining personal respite and providing benefits to the relative.

i. Experiencing support through the home-based treatment

The most frequently mentioned benefit from use of the community mental services by carers was that they benefited from the home-based treatment provided by the community mental health teams. Some of the carers recounted that they felt supported by the home visits from the medical staff. They stated that recurrent visits of the staff nurses helped them to reduce their caring problems. Carers experienced support when they received good services from the community mental health teams. They considered the services good when the teams show their concern towards them and their family members. For example, a female Chinese mother who aged 57 years who lives in the urban area reported that she had a good relationship with the staff from the community clinic, which made her feel appreciated by the mental health professionals.

Some caregivers also mentioned that the positive attitude of the staff influenced the caregivers' satisfaction towards the services. An example of this feeling is that a multiple carer (a brother to siblings with schizophrenia) described the staff's positive attitudes when they show interest over the patient's activity whilst staying at home. More interestingly, this multiple carer treated the staff nurse like his own sister. This shows a strong bonding between them. Consequently, when the carers are satisfied with the community mental health services they tend to support any programmes organised by the same service provider.

Based on the information above, it shows that caregivers who have received the community mental health services benefited from it through the support from the mental health professionals. Caregivers who were experiencing support were found to be satisfied with the services. One of the factors that contributed to this satisfaction was a good relationship between the service providers and the carers.

Clearly, caregivers explained that the staff's positive attitudes made them feel warm and happy, which in general meant they had a positive perception towards service use. The positive perception is important for continuity of the service delivery, which was noted by the carers themselves.

ii. Gaining Information and Practical Knowledge

Carers indicated that the community mental health services provided them an opportunity to gain new knowledge. Through support groups and other service programmes, they said that they were able to gather practical suggestions, learn the necessary information, develop new skills and learn about resources. For example, a rural Malay mother who aged 52 years explained that she learned about facts on mental illness and ways to handle her son's problems through the community clinic's programmes.

Besides, some of the carers recounted that they had learned the necessary information about mental illness when participated in the family support group organised by the community clinics. They recalled that through participating in the support group, they were able to learn from each other and from the service professionals. For instance, carers in the city area had formed family support group called the *Kinta Action of Mental Illness (KAMI)*,

and most of the members are caregivers to people with mental illness. Generally, caregivers who are actively involved in the family support groups seem to receive more benefits, which help them to care for their mentally ill patients. The family support group is a platform to meet and exchange experiences with others caregivers.

iii. Experiencing Sense of Community

As noted, carers discovered that they become more positive with their caregiving roles when they receive support from other carers. They notice that they were able to find a sense of community with other carers who had similar experiences. For example, an Indian sister who lives in the urban city commented that KAMI provides a chance to release their negative emotions. She said,

“KAMI is meant to be a place for carers to enjoy activities and appreciate the experience of caregiving for their relative”.

Likewise, a husband who lives in the rural area also pointed out that the family meetings organised by the community clinic enables the carers to exchange opinions and gather suggestions from other carers. By becoming involved in the support group, caregivers can develop their own social support network, which can provide a space for them to rest. This entertainment can be realistic when members of the support groups get together and enjoy activities that they think are beneficial to them as a carer and also as a human.

iv. Receiving a Financial Support

Further, some of the carers reported that they receive financial support from the welfare department whilst utilising the community mental health services. They noted that the financial support is meant for patients’ treatment, especially to facilitate the required care. For example, one carer recounted that he is happy with the commitment of the staff in the community clinic who are able to assist him with financial support to be used for his brother’s treatment.

Most of the participants in this study needed financial assistance to be able to care for their mentally ill relatives. One of the benefits of using the mental health services is that caregivers found that they were introduced to other social services that provided financial support. Caregivers who received financial support were grateful because it helps them to focus on their caregiving roles when one of the caregiving constraints has been tackled. Generally, the financial support not only helps them to care but also benefits other family members as well.

v. Receiving Emotional Support through a Counselling Service

Furthermore, some of the carers recounted that they obtained emotional support through the counselling services provided by the community clinics. For example, a Malay mother who lives in the rural area employed a counselling service in the community clinic to overcome her caring dilemmas. She said,

“I know where to go when I need to talk to someone about my hassles; I use a counselling service provided by the staff in the community clinic. I think the counselling service is good because it made me feel relief. Now I recommend it to other carers as well, especially when they face problems with their families.”

iv. Receiving Personal Respite

Furthermore, caregivers were able to recognise specific personal problems or emotions that prevented them from enjoying their caregiving role. They managed to identify specific personal gains such as having more time for themselves, having some freedom, feeling relief and respite, being able to get away and being able to relax. For some carers, being away from their relatives through support groups, day centre, or similar provided them with a form of respite and a time for respite. This respite gave them the strength to continue their caregiving role. For example, a Mother recounted that the psychosocial-rehabilitation centre is like a day centre that enables her to rest and reduce her caring workload when her daughter is following the centre's programmes. Most of the carers also found that it is important to have a temporary place to put their relative so that they can enjoy their social life. A mother said,

“Every time she is in the clinic, I have my own time for myself; I can go out to meet my friends, do shopping and go to the religion class at the mosque.”

It was noted that caregivers who utilised the psychosocial-rehabilitation centre as a day centre benefited from their own respite. This was an important aspect in their caregiving life because it gave them time to recuperate and reenergise themselves after feeling tired from their caregiving role. During this time, they can enjoy their own activities without having to think about their mentally ill patients plus they found a way for a “win-win” situation for both parties.

vii. Providing Benefits to the Relative

Carers asserted that the use of the psychosocial-rehabilitation centre is beneficial to the mentally ill person. They stated that the patients were trained and learned a variety of life skills, especially domestic skills, after following the psychosocial-rehabilitation programmes in the community clinic. Carers also commented that the support received from the community clinics is helpful to avoid deterioration and prevent the relapse of their relatives. Some of the carers found that the use of services helped to stimulate and provide companionship for their relative.

b) Barriers to Service Use

Although many caregivers experienced personal benefits when using community mental health services, there were a few caregivers who used little or no support from community programmes. Consequently, it was not surprising to find several reasons given by family members for their reluctance to use services. As in the analysis of the benefits, phrases that suggested these reasons were first analysed for patterns that were arranged in subcategories and then clustered into broader categories. The broad categories included lack of attention, accessibility issues and concerns over quality.

i. Lack of Attention

One of the reasons described by those caregivers who had negative perceptions towards the community mental health services was the lack of attention from the mental health professionals. They complained that some professionals were not concerned about their needs. For example, a Chinese father who lives in the urban area reported that the staff did

not fulfil his caring needs and only concentrated on his daughter's medication. This situation made caregivers felt reserved towards the staff in the community clinic. Most of the caregivers in this study, agreed that the doctors were too busy with other patients and neglected the caregivers' needs to the last priority.

In addition, some of the caregivers in the urban area commented on the home visit by the staff of the community clinics, that is, they are patient-focused and not family-centred. Through the use of community mental health services, they indicated of feeling hopeless, disappointed, useless and unsupported because of the lack of attention from the staff in the community clinics. More interestingly, a Malay mother in the rural area complained that she has been ignored and neglected by the staff of the community clinic. This carer is a stepmother to a mentally ill patient who claims to play a major role in caring for her stepdaughter. At the time of the interview, she was the only person who stays home with the patient. When the researcher explained the aims of the research to her, she started to complain that she has never been recognised as the main carer by the staff in the community clinic. She claimed that the staff always talked to her husband and made her felt ignored.

The lack of attention or concern from the mental health professionals made the caregivers felt dissatisfied with the services. Caregivers felt left out from the mental health services when the doctors or staffs in the community clinics were unable to perform their needs of caregiving. This was exacerbated when the professionals did not correctly identify who is the main carer actually providing care for the mentally ill person at home causing them to feel ignored by the services. Of course, when they are dissatisfied with the services, they become reluctant to use the mental health services. Therefore, this research has provided the carers with an opportunity to complain about their perceptions concerning the mental health services.

ii. Accessibility Issues

Although the community clinics were mainly set up to promote community care, these clinics are located in the downtown area which is not accessible to some of the family caregivers. They reported that the distance between the clinic and their house was a bit far and inaccessible, especially for carers dwelling in the rural area. For instance, a Malay wife in the rural area said,

“The distance between my house and the clinic does not permit him to go to the clinic. Furthermore, I have an eyesight problem and am unable to send him to the clinic. I have to depend on my other healthy children but they are unable to send their brother because of the different areas of the clinic and their work places.”

It has been noted that the location of the clinic limited the caregiver use of the community mental health services, especially in the rural area. Mostly, the carers need support from others to solve their accessibility issue. For instance, a Chinese father in the rural area also identified that,

“The clinic is far and makes it difficult for me to go there. Sometimes, I have to ask a friend who has a car to take us to the clinic.”

Not only did the carers in the rural area comment on the location of the clinic but the urban carers as well. They pointed out that the location of the community clinics are not strategic and are inconvenient for them to send and take the patients everyday. The trouble is

not just for them as a carer but also for the patient who might refuse to go to the clinic due to the travel difficulties. Carers also remarked on the transportation problems and suggested a solution to the service provider to tackle the issue. For instance, an Indian sister to a mentally ill person reported that sometimes she is unable to send her sister to the clinic and as a result her sister has to stay home for the whole day. Therefore, she suggested that the centre should have a transportation service to collect and send the mentally patients home.

iii. Concern over Quality of Services

Some of the carers expressed their worry about the quality of the mental health services. Specifically, they were concerned about the shortages of adequate staff, frequency of the staff changes, about the programme and activities plus the need of the service evaluation to monitor the psychosocial-rehabilitation centres. For instance, a Chinese father critically reported that the number of staff in the psychosocial-rehabilitation centre was inadequate and that the centre was often closed when the staff in charge had a meeting or was sick. There is obviously a need for adequate backup to maintain the services.

Moreover, another Chinese carer expressed his confusion regarding the staffing in the community clinic, which changed frequently. As a retired police officer, this carer could not tolerate the negative attitude of the staff in the clinic. He stressed that the community clinic needs to have disciplined staff and some kind of services evaluation to monitor the community services.

Another quality issues raised by the caregivers is the programmes and activities provided in the community clinic. Some of the caregivers noticed that the patients refused to go to the community clinics because the programme is not interesting. For example, a Chinese mother who lives in the urban area said,

“She tells me that the programmes in the centre are boring. I think that is a reason why the number of service users in the centre decreases every year.”

Besides, a few carers remarked that the programmes in the community clinics are unsuccessful in attracting the patients’ interest to go there. Therefore, these caregivers proposed that the programmes need to be more interesting and should be specific to the different needs of the patients according to their ages of development.

DISCUSSION

Overall, the majority of the caregivers who were concerned about the quality of the services came from the urban area. Only a single rural caregiver reported about the staff’s negative attitude on the quality of the programme. He commented about getting inadequate attention from the service providers, specifically, highlighted the inconsistency of gaining caregivers’ services and neglecting of caregivers’ actual needs. In addition, caregivers expressed their concerns about the lack of staff, lack of monitoring systems and lack of programmes or activities that were provided for their relatives. A few carers provided some suggestions to improve the quality of the mental health services. Most of the Chinese and Indian caregivers in this study expressed their concerns about their experiences of using the community mental health services compared to Malay sample.

Another issue is relating to transportation. It was reported as one of the service barriers that need to be tackled if the service providers plan to provide community mental health

services to the patients and their families. This is important in order to increase, the number of patients following the programmes in the community clinics. Therefore, transportation should be one of the important factors that need special attention in the process of social planning level specifically when providing the community services to the patients and their families. Mental health professionals also are required to consider all suggestions made by the family caregivers in helping to ensure the quality of the services.

On the other hand, many family caregivers in this study reported gaining benefits. This indicates a positive experience when utilising the community mental health services in their community. Many caregivers were able to identify their benefits from the use of the community mental health services provided in the community clinics. They also acknowledged the benefits gained from their community mental health services for their mentally ill family members. All these experiences determined the importance of role from the community mental health services to the patients and their families. Nevertheless, despite these benefits, caregivers also identified factors that constrained them to use the community mental health service that is available in their communities due to geographical and organisational factors. These findings support and add to the knowledge about the benefits of and barriers to service use by family caregivers of schizophrenic patients especially in developing countries. The findings of this study were supported by previous studies include the benefit of gaining knowledge through the use of community services (Winslow 2003; Gitlin et al. 2001; Archbold et al. 1990). Personal respite and providing benefits to the patient found in this study is similar to other studies in developed country like UK (Winslow 2003) and US (Mittleman et al. 1996). Meanwhile, the finding of emotional support through a counselling service to improve well-being corroborated with the study conducted by Toseland and Smith (1990) and Winslow (2003).

Many researchers on family caregiving also supported the findings from this study on the barriers of service use identified by the family caregivers. These researchers reported that the concern over the quality of community services became an issue to the family caregivers in developed (Liken & King 1995; Mullan 1993) and developing countries (Cheung & Snowden 1990). Similar findings to this study, some of the caregivers reported about the quality of community services, however, most of the concerns originated from the Chinese and Indian caregivers. One of the reasons is that these caregivers had higher education background compared to Malay caregivers. It also can be concluded that non-Malay caregivers in this study had high expectations towards the community mental health services whilst the Malay caregivers more satisfied with the services. This finding is supported by Salleh (1994) who discovered that Malay families did report about the community services despite the negative symptoms of schizophrenia from caring burden. Salleh also discovered that there was some of the Malay caregivers who reported about the lack of attention received from the staff in the community clinics, especially, during the home visit. These caregivers showed their needs to be recognised by the mental health professionals. They also revealed the lack of transportation became a barrier for them to access and use the community mental health services in Malaysia. This study suggests that there is an critical need for the Ministry of Health in Malaysia in providing more accessible community clinics in order to provide community mental health services to fulfil the urgent needs of patients and their families needs.

CONCLUSION

Findings from this study suggested valuable perspectives from the family caregivers' experiences of caring need to consider when providing services for mental health clients in community settings. The family intervention need to be targeted at the ground level to

understand caregivers' needs on their own right. This study has shown that, although a few barriers continue to exist, the family caregivers also reported experiencing benefits from using the service. Overall, it is important to include both positive and negative aspects of service use when implementing community mental health services for schizophrenic patients and their families especially in developing country like Malaysia.

References

- Archbold, P., Stewart, B., Greenlick, M., & Harvath, T. 1990. Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*, 13, 375–384.
- Aziz, A. A., Salina, A. A., Abdul, K. A. B., Badiah, Y., Cheah, Y. C., Nor, H. A., Ruzanna, Z. Z., Chee, K. Y. 2008. The national mental health registry (NMHR). *The Medical Journal of Malaysia*, 63, 15-7.
- Barnes, D., Carpenter, J., & Bailey, D. 2000. Partnerships with service users in interprofessional education for community mental health: A case study. *Journal of Interprofessional Care*, 14 (2), 189-200.
- Barriball, K. L. & While, A. 1994. Collecting data using a semi-structured interview. *Journal of Advanced Nursing*, 19, 328–335.
- Carpenter, J., Schneider, J., McNiven, F., Brandon, T., Stevens, R., & Wooff, D. 2004. Integration and targeting of community care for people with severe and enduring mental health problems: Users & experiences of the care programme approach and care management. *The British Journal of Social Work*, 34 (3), 313-333.
- Chang, K. H., & Horrocks, S. 2006. Lived experiences of family caregivers of mentally ill relatives. *Journal of Advanced Nursing*, 53 (4), 435-443.
- Chen, F. P., & Greenberg, J. S. 2004. A positive aspect of caregiving: The influence of social support on caregiving gains for family members of relatives with schizophrenia. *Community Mental Health Journal*, 40 (5), 423-35.
- Cheung, F. K., & Snowden, L. R. 1990. Community mental health and ethnic minority populations. *Community Mental Health Journal*, 26, 3, 277-91.
- Dixon, L., McFarlane, W. R., Lefley, H., Lucksted, A., Cohen, M., Falloon, I., Mueser, K., Sondheim, D. 2001. Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services*, 52 (7), 903-910.
- Doornbos, M. 2002. Family caregivers and the mental health care system: Reality and dreams. *Archives of Psychiatric Nursing*, 16 (1), 39-46.
- Fadden, G., Shooter, M., & Holsgrove, G. 2005. Involving carers and service users in the training of psychiatrists. *Psychiatric Bulletin*, 29 (7), 270-274.
- Flick, U. 2006. *Designing Qualitative Research*. London: SAGE.

- Gitlin, L., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. 2001. A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *Gerontologist*, 41(1), 4–14.
- Hsiao, C. Y., & Van Riper, M. 2010. Research on caregiving in Chinese families living with mental illness: A critical review. *Journal of Family Nursing*, 16 (1), 68-100.
- Lefley, H. P. 1996. *Family Caregiving in Mental Illness*. Family Caregiver Applications Series, 7. Newbury Park, Calif: Sage Publications.
- Lefley, H.P. 1998. Families, culture, and mental illness: Constructing new realities. *Psychiatry*, 61 (4), 335-355.
- Levin, E. 2004. *Involving Service Users and Carers in Social Work Education*. London: SCIE.
- Liken, M., & King, S. 1995. Home health aide services: Barriers perceived by dementia family caregivers. *Home Healthcare Nurse*, 13(6), 60–68.
- Magliano, L., Fiorillo, A., De, R. C., Malangone, C., & Maj, M. 2005. Family burden in long-term diseases: A comparative study in schizophrenia vs. physical disorders. *Social Science and Medicine*, 61 (2), 313-322.
- Malaysian Psychiatric Association 2010. *Survey: Stigma keeps millions with anxiety disorders from treatment*. Retrieved from http://www.psychiatry-malaysia.org/html/consensus_intro.shtml.
- Marsh, D. T. 1999. Serious mental illness: Opportunities for family practitioners. *The Family Journal*, 7 (4), 358-366.
- Marsh, D. T., & Johnson, D. L. 1997. The family experience of mental illness: Implications for intervention. *Professional Psychology, Research and Practice*, 28 (3), 229.
- Ministry of Health. 2008. *Health Facts 2006*. Ministry of Health Malaysia. [On-line] Retrieved from http://www.moh.gov.my/images/gallery/stats/heal_fact/health_facts_2006.pdf
- Mittleman, M., Ferris, S., Shulman, G., & Levin, B. 1996. A family intervention to delay nursing home placement of patients with Alzheimer's disease: A randomized controlled trial. *Journal of the American Medical Association*, 276, 1725–1731.
- Mullan, J. 1993. *Barriers to the use of formal services among Alzheimer's caregivers*. In S. Zarit, L. Pearlin & W. Schaie (Eds.). *Caregiving Systems: Informal and Formal Helpers* pp. 241–259. Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.
- Ritchie, J., Spencer, L. & O'Connor, W. 2003. Carrying out qualitative analysis. In Ritchie, J., & Lewis, J. *Qualitative Research Practice: A Guide for Social Science Students And Researchers*. London: Sage Publications.

- Roick, C., Heider, D., Toumi, M., & Angermeyer, M. C. 2006. The impact of caregivers' characteristics, patients' conditions and regional differences on family burden in schizophrenia: A longitudinal analysis. *Acta Psychiatrica Scandinavica*, 114 (5), 363-374.
- Salleh, R. M. 1994. The burden of care of schizophrenia in Malay families. *Acta Psychiatrica Scandinavica*, 89, 180-185.
- Schene, A.H., Van Wijngaarden, B. & Koeter, M. W. 1998. Family caregiving in schizophrenia: Domains and distress. *Schizophrenia Bulletin*, 24 (4), 609-618.
- Schwartz, C., & Gidron, R. 2002. Parents of mentally ill adult children living at home: Rewards of caregiving. *Health & Social Work*, 27 (2), 145-154.
- Tessler, R. C., & Gamache, G. 2000. *Family Experiences with Mental Illness*. Westport, Conn: Auburn House.
- Tew, J., Gell, C. & Foster, S. 2004. Learning from Experience: Involving Service Users and Carers in Mental Health Education and Training. Nottingham: NIMHE/Trent Workforce Development Corp.
- Toseland, R., & Smith, G. 1990. Effectiveness of individual counseling by professional and peer helpers for family caregivers of the elderly. *Psychology and Aging*, 5(2), 256-263.
- Webb, S. 2008. Modeling Service User Participation in Social Care. *Journal of Social Work*, 8 (3), 269-290.
- Winslow, B. W. 2003. Family caregiver's experiences with community services: A qualitative analysis. *Public Health Nursing*, 20(5), 341-348.
- Wooff, D., Schneider, J., Carpenter, J. & Brandon, T. 2003. Correlates of stress in carers. *Journal of Mental Health*, 12 (1), 29-40.
- Zahiruddin, O., & Salleh, M. R., 2005. Burden of care in schizophrenia: Implication of psychopathology of the illness. *Malaysian Journal of Psychiatry*, 13 (2), 34-40.
- Mohd Suhaimi Mohamad, Sheau Tsuey Chong, Suzana Mohd Hoesni, Nasrudin Subhi, Norulhuda Sarnon & Salina Nen
 Pusat Pengajian Psikologi Dan Pembangunan Manusia,
 Fakulti Sains Sosial Dan Kemanusiaan
 Universiti Kebangsaan Malaysia
 Email: msuhaimi@ukm.my