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Care Demands-related Concerns and Perceived Service Needs of Families of People with Mental Illness in the Community

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Abstract

Owing to reduced inpatient stays, people with mental illness (PMI) were often discharged from the hospital in ‘acute’ conditions. During this transition period of fragility, the relocation of care from hospital to home has tremendous impact on every aspect of a family’s life as they need to face a challenging task of caring especially when they are ‘not ready’ and ‘ignorant’ about the chronicity and severity of the illness. Furthermore, where economic and psychological support is concerned, those who are undertaking this task may require significant professional guidance. Aims: This study examines the experiences of 100 families in caring for people with mental illness in the community. Methods: Qualitative interviews were conducted in their homes within three Malaysian states of Sabah, Sarawak and Johor in year 2013. Results: Three themes emerged from the findings of ‘care demands related concerns’ of these families. These include theme (1): care provision related concerns of families which were related to the needs of people with mental illness for continuing care provision, their non-compliance with medication and relapse, altered sleep pattern, limited self-care ability, behavioral problems and also social isolation. Theme (2): perceived availability of resources of service provision/support which were related to activities planned for the families before the discharge of the people with mental illness and theme (3): family members perceived service needs whereby they informed of their needs such as continual health care through home visit, provision of financial aid, job coach service, centre for care provision of PMI and rehabilitative programs.

Keywords: Community, People with Mental illness, Non-compliance, Relapse, Social Isolation

Introduction

Mental illness in one family member can impact on various aspect of the family life: work, income, leisure time, personal health and social relationship with friends, neighbors, colleagues and even extended family. Experiences of social isolation resulting from their avoidance of family celebrations or other recreational activities are common. Furthermore, marital discord and family conflicts may increase
dramatically. Siblings and their parents’ experience of fears, difficulties in functioning and significant grief reactions which required counseling or medical attention have been reported.\textsuperscript{1-3}

The family who are managing a person with mental illness at home may be threatened by the need for a regular routine for instance, they may need to contend with reverse sleep cycles as the person may sleep all day and be awake during the night. One of the more insidious stressors experienced by the family was the lack of opportunity to ‘let off some steam’ to vent their tremendous frustrations and disappointments associated with mental illness. Therefore, the family who manage people with mental illness at home may be seen by others as sacrificing their lives, martyring themselves.

Hence, in this era of shortened hospital stays, plans of how best to effect a smooth transition of continuity of care from hospital into the community is of imperative significance. This is because, a stressful transition coupled with unmet needs could lead to vulnerability, decompensation, poor reintegration into the community and ultimately re-admission to hospital. Moreover, the families still needed the support not only in the continuity of care but especially so in times of crisis or when they feel depleted emotionally or physically hence unable to carry on.\textsuperscript{4-5}

**Background**

With the objective to reduce stigmatization of the illness and deinstitutionalization of the people with mental illness (PMI), the locus of care has moved from hospital care to be in the community since about two decades ago.\textsuperscript{6} With shorter inpatient stays, PMI often leave the hospital in acute conditions with the needs for prompt and focused care from their families which include the needs to manage the frequent crises due to the chronic nature and severity of the illness, lower level of social adaptive and other functions.\textsuperscript{7}

In Malaysian setting, when a person with mental illness is discharged from the ward, he/she is directly brought back to their home and into the community. The family members who are either equipped with or without the knowledge on how to ‘care’ for them at home need to ‘accept’ the responsibilities of caring. It is very common to hear that the family members are actually ‘scared’ of the patient but they have no choice. Hence, family members who live with people with mental illness may be ‘at the edge of psychosis all the time’ or living with constant fear which is not healthy. In addition, they will be varied in their capacity for socialization due to stigma. While some were isolated to the point of being reclusive, suffered from depression, alcohol abuse and chronic medical conditions, while others, socialized inappropriately or engaged in high risk behavior including substance abuse as a result of stress.\textsuperscript{8}

This relocation of care from hospital to home of the PMI has tremendous impact on every aspect of the families as carers. These include their work life, income, leisure time, personal health and social relationship with others. Families’ experiences of social isolation resulting from their avoidance of family celebrations or other recreational activities are common. There is an increased marital discord and family conflicts; siblings and their parents experienced fears, difficulties in functioning and significant grief reactions.\textsuperscript{1-3} Families might need professional guidance and supports.\textsuperscript{9}

This is an interesting phenomenon to
explore whereby the magnitude of the problem whereby family who live with people with mental illness need to learn to become ‘expert’ in pharmacological as well as psychosocial rehabilitation. An appropriate and effective home-based and community support systems need to be coordinated to play a central role for smooth collaboration, cooperation and communication between the family, professional caregivers and people with mental illness.\(^\text{10}\) This will help to minimize the gap that appears among the elements of an uncoordinated psychiatric system and fragmented services resulting in the families to be in the dark, feeling isolated and not knowing what to do next.

This study hopes to strengthen/add on to the knowledge and insights on the care and facilitate an evidence-based decision making in relation to continual care provision for PMI after their discharge from the hospital into the community setting.

**Aim**

This study aimed to examine the experiences of caring for the PMI in the community.

**Methods**

A qualitative approach was adopted to explore the families’ experiences of caring for people with mental illness in the community. The families of PMI were interviewed using the interview question guide which explored the predefined topic in greater length and depth. The researcher gains the understanding of their views by using a language that was natural and understood by them.

Before conducting this study, ethical consideration had been sought from the Medical Research and Ethics Committee; Ministry of Health and the National Medical Research Register. A series of informal meetings and phone calls with the senior personnel of the mental institutions were done in order to gain organizational support and indirectly helped in the recruitment of participants. Only families who consented to participate in the study were recruited.

**Study settings and recruitment of participants**

100 families were recruited based on a non-probability, purposive sampling. To ensure that maximum variations of family’s perspectives of care experiences, families for this study who were of various ethnicities were recruited from three selected government hospitals in the States of Sarawak, Sabah and Johor. Register of names of PMI who were under the community follow-up care team home visits were screened through as a way to access their families. Sample size was determined by data saturation. Interviews were stopped when no new theme could be derived from the data.

**Data collection**

Data collection was conducted between July 2013 to November 2013 in the participants’ home after prior informed consent for participation was obtained. The interview was done face to face and audio-recorded in their homes. All interviews, each lasting from about half to one hour, were conducted in English, Bahasa Malaysia, Sarawak local dialect and Iban language. Field notes were also taken immediately after the interview.

**Data Analysis**

Textual data from the interview were thematically analyzed to obtain an in-depth understanding of the experiences of families caring for people with mental illness in the community. This involved preparing and organizing of textual data for analysis, reading through textual data, coding to
generate themes, representation of themes and interpretation.

Results

Theme (1): Care provision-related concerns of families

a. Lack of confidence for continual care provision

There is an issue of lack of confidence for continual care provision of the PMI who were discharged from the hospital. In particular, families perceived it as a challenge when they had to deal with the PMI’s behaviour. This caused them to be discouraged and fatigued with the caregiving role as evidenced from the following excerpt.

*The hospital should keep him a little longer. We don’t really know how to deal with him at home especially when he can just turn violent. I just don’t know how to describe to you when this happens.*

*Sometimes, he did not want to take his medicine....when I ask him to take, he will get angry with me. Sometimes, he will just slam his room door.*

b. Behavioural related concerns

One of the concerns of family members in their care provision of PMI who were discharged from hospital was behavioural-related. These include the PMI’s nature of being hot tempered or easily irritated or angry as illustrated by the following excerpts:

*If we ask her to help with house chores, she will do....but need to be asked to do...and sometimes she just got angry when being asked.*

He smokes a lot... he will get angry if there is no cigarette.

*He can just turn violent. I just don’t know how to describe to you when this happens.*

The family members noted that it was a burden to them when the PMI under their care smoked a lot and this added to their financial expenses as illustrated in the following excerpts:

*Oh...he smokes a lot...I need money to have the stock of cigarettes... otherwise he will get angry if there is no cigarette.*

*He always want to smoke. As he has no money, I have to buy him the cigarettes. You know, now that the cost of the cigarettes has increased....so, it pinches on my budget most of the time. But yet, I have no other choice but to buy the cigarettes.*

c. Concern related to non compliance with medication and relapse

Issue related to PMI’s non-compliance with medication and relapse is one of the most prominent issues encountered. The family members had to supervise and coax the PMI to take their medication as illustrated in the following quotes by the mothers:

*Sometimes she takes her medicine and sometimes she didn’t...or she misses a pill or two.*

*Sometimes she just did not want to take her medication.*

*I need to crush the pills and mix with her food, otherwise, the medicine will be just left lying there. If she know about me mixing her food with the medicine, she don’t want to take the food also.*
**d. Concerns of altered sleep-wake pattern**

Most of the time, the PMI slept during the day.

*Since she is discharged from hospital, she is doing nothing....sleeping most of times.*

He sleeps a lot especially during the day.....but at night, he will sleep very late. Sometimes he sleeps at 5 am in the morning when I wake up to prepare breakfast for the family.

He likes to wander around especially at night and came home late which worried the family members.

**e. Concern of limited self care ability**

Family members expressed their concerns about the PMI’s self care ability due to the altered level of cognitive functions and limited awareness of dangers as indicated by the following quote:

*He likes to wander around especially at night and came home late which worried the family members.*

He smokes a lot. Most of the time, he just throw the cigarettes butt anywhere. One time I caught him throwing part of his unfinished cigarette on his bed. What worries me is that, this poses danger not only to him but all of us.

Some mothers indicated their concerns as they still need supervision in relation to their own hygiene needs, as stated by one mother:

*He doesn’t like to take bath...have to force him.*

**f. Concerns related to tendency of social isolation**

Another of the concerns as expressed by some of the family members was related to the tendency of social isolation among the PMI who did not talk much but and kept to themself most of the time:

*Most of times, she keeps to herself in her room...don’t know what she is doing there. He does not have any friends since his illness sets on him.*

He refused to meet with his friends. Looks like, he prefers to be on his own.

He is not interested to be involved in any activity especially those involving a lot of people....so he will stay at home and sleep.

**g. Lack of family resources for continual care provision**

Family members expressed their preference for PMI to be continued with hospital care due to problems of not having adequate family resource for continual care provision of family member who are PMI at home. The following quote is illustrative:

*There is nobody to take care of him at home as all of us have our own responsibilities ....both of us are working while the other siblings are either working or at school....so if possible, better (for him) to be staying at the hospital as there are staffs who know how to take care of the patient there.*

Its better for him to be at the hospital. There is nobody to look after him at home while everybody is at work. I am scared to leave him on his own without any supervision.
h. Positive and supportive of early discharge from hospital

However, there are also family members who viewed that if the PMI’s condition is stable, it is good for the PMI to be at their own home as family can take care of them.

If her condition is stable, then there is no reason for her to stay at the hospital. I want her to stay at home with me because she is my daughter. I can take care of her at home and I can see how she is getting on.

I can see that my son is doing fine as long as he takes his medicine. I would prefer my son to be at home with me because I am worried that he will be lonely at the hospital. At home, I can take care of him.

Theme (2): Perceived availability of resources of service provision / supports

Various kinds of activities were being planned for the families before PMI are being discharged from the hospital. The common activities include health education and family therapy whereby the families need to understand the nature of the illness, the importance of drug compliance, what they should do in case of emergency or if patient relapses.

When he is admitted, the doctor tells us about his illness. Before discharge, we are being informed about the importance of drug compliance and follow up care.

The staff were very kind. They asked me and the other families to attend family therapy which I find very useful in understanding my son’s illness.

Theme (3): Family members’ perceived service needs

With regards to the various problems/issues as encountered by families of PMI, these families perceived the needs for formal service provisions. These include the needs such as continual health care through home visit, provision of financial aid, job coach service, centre for care provision of PMI and rehabilitative programs.

a) Continual health care: home visit

Majority of the families recommended that they still need the health professionals’ care provisions. These include doing home visits to monitor the PMI’s condition, and providing assistance with counseling the PMI, in particularly their medication. As requested by one mother:

If possible, the hospital staff to continue doing home visits to their home so that I have somebody to ask if I have problems or doubts....like medication.

However, there are families who were reluctant for health professionals from clinic or hospital to visit their homes due to fear of being stigmatized by the neighborhood

I don’t like the staff coming to our home. Otherwise, all my neighbors will know that our brother is mentally ill. I will bring him to the hospital for follow up.

b) Provision of financial aid

Formal support from the social welfare agency for families in term of financial aid is deemed a need as most of the PMI depended on their families. As lamented by one family member:
If possible, financial aid is given by the government for this type of people with mental illness...our family are poor...no money to cater for his needs...especially he likes to smoke...yet he is not working...depending on me to give him money to buy his cigarettes...so difficult like this.

c) Job coach support service

Formal support such as job coach service for job placement where possible for the PMI who are stable and independent are very much desired by the families. The following quote is illustrative:

If the government can provide or have job placement for people with mental illness is very good...my son is stable and independent....just that nobody want to take him to work.

d) Centre for care provision

Some families recommended a nursing home or centers which are affordable whereby those who are unable to take care or nobody to take care at home can send their relatives who are mentally ill to be cared for. As voiced out by one family member:

Nobody to take care of him here...you can see that my mother is old already and needed care too...and here another one like this...difficult...if the government can provide a center which is affordable would be good....as there are staff to take care of this kind of people.

e) Rehabilitation program

Invariably, a rehabilitation center is of importance to improve functions of the PMI in the community, as reiterated by one family member:

The hospital needs to have rehabilitation program, which cater to the needs of the patient.

Discussion

The discharge of people with mental illness from hospital into the community posed a challenging time for both people with mental illness as well as their families. For many PMI, residual symptoms may still remain and despite follow up care arranged for them, transition experiences from hospital to community often is experienced as being complex and disturbing.

Family members viewed that if the PMI’s condition is stable, it is good for them to be at their own home as family can take care of them. This finding is consistent with previous research whereby if patients felt supported by their family members, this can be a key feature in the successful adjustment to the community after discharge. However, some family members viewed that it is better for the patient to be in the hospital as there are hospital staff who knew how to take care of patients. Moreover, if the patient is in the hospital, they are confident that the patient is in “good hands” especially when they have nobody to take care of the patient at home.

Generally, family members expressed that they are not confident of taking care of the PMI at home related to behavioral control and administration of medications. They perceived they do not know how to control patient’s behavior especially when they turn aggressive or show their temper which caused them to be discouraged and fatigued with the caregiving role. This suggest that family interventions targeting symptoms management and their roles in medication
adherence seem warranted. This is consistent with findings by Nehra, Chakrabarti, Kulhara & Sharma, (2005)\textsuperscript{12} found that family coping styles can be identified and used to plan interventions to reduce the burden of family members who help to manage the patient at home. This is because successful management largely depends upon family support.

Psychological distress related to the caregiving role and burnout of families over time should not be neglected as this issue requires a more consistent intervention to ensure continuous support to communicate treatment goals related to overall patient functioning and integration into the community. This findings is consistent with findings by Saunders (2003)\textsuperscript{13} who suggested that mental health professionals should assist both patients and their caregivers in their recovery-oriented services such as strategies for relieving symptoms through educating about role of medications. This is due to the fact that variables associated with recovery include domains such as life satisfaction, hope and optimism, knowledge about mental illness and recovery and empowerment.\textsuperscript{5}

Where problems faced by family members were concerned, there was a consistent tone of frustration and discouragement as family described situations as worrisome. The needs related to management of symptoms, compliance to medication and other specific needs include those related for structured activities, employment, self-care and hygiene. Since patients and families accepted their discharge and follow up plans, a comprehensive plan of care which include family involvement would enlist treatment goals of the programs for the patient. Therefore, the focus of supportive family education such as more intensive behavioral family therapy for developing carer competence is deemed of significance not only to reduce carer stress and burden, but to improve coping, social support and quality of life.\textsuperscript{14-16}

**Recommendations**

Comprehensive treatment programs that address financial, occupational and social factors for patients with mental illness need to be focused on their needs. The elements of intervention should be carer focused, patient focused or both. This is to ensure that the targeted outreach program and the community follow up care consistently provide structure and ongoing professional support to both the people with mental illness and their families.

As the front line professionals who are in direct contact with people with mental illness and their family in the community setting, nurses may have to be trained to deliver more intensive interventions such as family support, family therapy and community support with the aim to improve coping hence reduce carer burden and improved mental health. The focus of supportive family education should move beyond information giving to developing coping strategies and support mechanisms for family members that enhanced the quality of life.\textsuperscript{17}

As for rehabilitation services, it should be focused on a culturally sensitive model with particular emphasis on education, work and independence as these would restore health and social functioning while establishing and maintain valued social roles. The users should not be passive players in the rehabilitation landscape but active participants shaping, as well as being shaped by, socio-medical pathways using personal coping mechanisms.
Conclusion

With the early discharge of people with mental illness into the community, an effective discharge planning is necessary to facilitate the transition period from hospital to community care. A personalized, comprehensive and structured discharge care plan is deemed important and requires attention not only to reduce relapse rates but assist people with mental illness to function at their best in the community. In addition, social support particularly as part of aftercare arrangements should aim to provide both practical assistance, information and general support such as skills training and interpersonal effectiveness. Adequate staffing, resource provision, organizational commitment and education of staff are an integral component of ‘discharge pack’ services to improve the continuity of service delivery and care between hospital and community mental health settings.

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