

Caregivers in schizophrenia: A Cross Cultural Perspective

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ABSTRACT

Background: Schizophrenia not only influences the lives of those affected but also those around them, especially the caregivers. This study examines the different determinants that are likely to contribute to the caregivers' perception of burden of care across different countries namely Malaysia and India, using the burden assessment schedule. **Aim:** The goals for this study were, to study the psychosocial and demographic aspects of patients suffering from schizophrenia, to study the levels of perceived burden of the Malaysian and Indian families caring for a relative with schizophrenia, and to study the determinants that contributes to the caregivers' perception of burden of care. **Materials and Methods:** The study was conducted in private hospitals, both in Malaysia as well as Mangalore after obtaining the necessary approval. 50 schizophrenia patients and their caregivers in Malaysia and India were chosen using the purposive sampling technique. The inclusion criteria were a minimum of 5 years since diagnosis of schizophrenia. **Results:** Although the Indian caregivers perceived difficulties in several areas such as finance, family relationship, well-being and health, they still perceived burden to be lesser compared to Malaysian counterpart. **Conclusion:** Intensified community based care can reduce burden.

Key words: *Burden, caregivers, cross culture, family support, schizophrenia*

INTRODUCTION

Schizophrenia is a serious, debilitating psychological disorder which not only influences the lives of those affected but also his family. As schizophrenia tend to become chronic, the functional decline leads to loss of social functioning, alters communication patterns in the family, leads to occupational difficulties, and puts a burden in the family. Family responses to having a family member with schizophrenia include care burden, fear and embarrassment about illness signs and symptoms, uncertainty about course of the disease, lack of social support, and stigma.^[2]

The caregivers have to deal with patients' symptoms, and help patients in activities of daily living.^[3] Caregivers look at several stressors including financial, family structure, and physical health demands among many others.^[4] Care giving could be stressful. Caregivers of persons with schizophrenia and other disorders

experience high levels of burden.^[5]

Burden of care can be conceptualized into two distinct components (objective and subjective). Objective burden of care is meant to indicate its effects on the household such as taking care of daily tasks, whereas subjective burden indicates the extent to which the caregivers perceived the burden of care.^[6] According to Creado *et al*,^[7] the relationship between coping styles and perceived burden of care is complex because caregivers subjectively report "burden." The burden of caregivers is more dependent on their appraisal of the condition of their patients rather than the actual illness.^[7]

Burden of care could be perceived differently in different cultures. Lin and Kleinman,^[8] suggests that in a socio-centric culture such as China, the primary emphasis is on social relationship; conventions and rules exist to shape social role and to sustain long

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term relationships. As a result, social isolations are less likely when an individual is affected with mental illness and becomes disabled. People living in Hong Kong are mostly Chinese in ethnicity, still influenced by the traditional Chinese Family orientation in which family members are obliged to take care of their family members, including the mentally ill.^[9]

Caring for dependent family members has been the primary role of women in Asian countries such as Japan, Taiwan, Malaysia, Philippines, and Indonesia. It has been reported that cultural issues dictate that the wife, adult daughter, or daughter in law, especially the first daughter in law are usually the primary care for the older relatives.^[10] In India care for other family members is an obligation and never considered as a burden. Thus, not all caregivers perceive the same burden as it varies according to the family support, cultural beliefs, and coping strategies.

According to the Global Burden of Disease Study, schizophrenia causes a high degree of disability, which accounts for 1.1% of the total DALYs (disability-adjusted life years) and 2.8% of YLDs (years lived with disability).^[11]

The assessment of YLD and non-fatal burden in Malaysia shows that 21% of the burden was contributed by mental disorders both in men and women.^[12]

Both Malaysia and India is a multi-ethnic, multi-cultural, and multilingual society. As a result of few mental health professionals and due to cultural beliefs, a large number of people end up going to faith healers and quacks, the result of which can lead to schizophrenia becoming chronic and leading to increased burden on the caregivers.

This study examines the different determinants that are likely to contribute to the caregivers' perception of burden of care across different countries namely Malaysia and India, using the burden assessment schedule (BAS).

The goals for this study were (1) to study the psychosocial and demographic aspects of patients suffering from schizophrenia, (2) to study the levels of perceived burden of the Malaysian and Indian families caring for a relative with schizophrenia, and (3) to study the determinants that contributes to the caregivers' perception of burden of care.

MATERIALS AND METHODS

Study site

The study was conducted in private hospitals, both in Malaysia as well as Mangalore after obtaining the necessary approval.

Study design

Questionnaire, Instrument rated, and cross sectional.

Sample selection

50 schizophrenia patients and their caregivers in Malaysia and India were chosen using the purposive sampling technique. In all 100 patients and their caregivers were studied. Help was taken from undergraduate medical students both in Malaysia and India in data collection. The patient and the caregiver were interviewed separately.

Criteria

The inclusion criteria were a minimum of 5 years since diagnosis of schizophrenia. Only those caregivers who volunteered to take part in the study were included; patients who were 18 years and above; diagnosis of chronic schizophrenia by the psychiatrist; only the primary caregiver was included i.e. the immediate family member who spent maximum time with the patient. Exclusion criteria were patients with co-morbid illness such as substance abuse; caregivers who were not related to the patient; and patients and caregivers who had difficulty in comprehending.

Instruments used

The BAS developed by Thara *et al.*,^[13] is a 40-item scale. It is a very popular and widely used scale to assess both objective and subjective burden experienced by the caregivers measuring nine different areas. The internal consistency for this scale was 0.80 as measured by the alpha coefficient. Each item has three responses "not at all," "to some extent," and "very much." Scores range from 40 to 120 with higher scores indicating greater burden. In addition, a questionnaire was used to tap the demographic aspect of the patient.

In this article, selected items from the BAS were analyzed for comparison between the two groups. For the sake of convenience, no attempt was made to give details on each of the three responses, namely "not at all," "to some extent," and "very much". Only the most appropriate response was presented for discussion. Data were analyzed using SPSS version 13.

RESULTS

Demographic characteristics of patient

Race

While all the patients studied in India belonged to Indian race, the Malaysian study included 40% Malay race, 34% Chinese race, 4% Malaysian Indians, and the remaining 22% indigenous people.

The Malaysian patients were comparatively younger than Indian patients. The numbers of female patients were comparatively more than male patients in both groups [Table 1].

Table 1: Demographic profile of the patients

	Malaysian	Indian
Mean age	38	43
Gender		
Male	48%	39%
Female	52%	61%
Occupation	48% unemployed	22% unemployed
Primary education	52%	77%
Mean income (MYR)	800	700
Relationship to patient		
Spouse	32%	18%
Parents	28%	42%
Children	10%	17%
Relatives	30%	23%

As seen in Table 2, the Malaysian caregivers were younger than the Indian caregivers. A majority of the caregivers in Malaysia were male (54%), while in India the caregivers were female (62%). The mean duration of care was higher (17 years) in India as compared to Malaysia (9 years).

Financial burden

68% of the caregivers in India, compared to 38% in Malaysia, were responsible to meet the patients' financial needs. Vast majority (44%) of the caregivers in India said that the current financial position is not adequate to look after the patient compared to 22% of the Malaysian caregivers. 40% of the Indian caregivers felt that the financial future worried them compared to 28% in Malaysia.

Family support

64% of the caregivers in India said that they received adequate support from other family members; however, only 32% of the Malaysian caregivers said that they received support.

Family relationship

A majority (36%) of the caregivers in India felt that they the patients illness prevents them from having a satisfying relationship with the rest of the family members compared to 24% in Malaysia. 30% in Indian caregivers felt that they are unable to give care to others in the family compared to 22% in Malaysia.

Marital relationship

90% of the Indian caregivers felt that they are having a satisfying relationship with their spouse in spite of their spouses' illness compared to the 34% Malaysian caregivers.

Sexual needs

Only a small number (4%) in India compared to majority (20%) in Malaysia responded by saying that their spouse was able to satisfy them sexually.

Table 2: Demographic profile of the caregivers

	Malaysian	Indian
Mean age	47	50
Gender		
Male	54%	38%
Female	46%	62%
Occupation	16% unemployed	12% unemployed
Mean Income (MYR)	1500	1000
Mean Duration of care	9 years	17 years

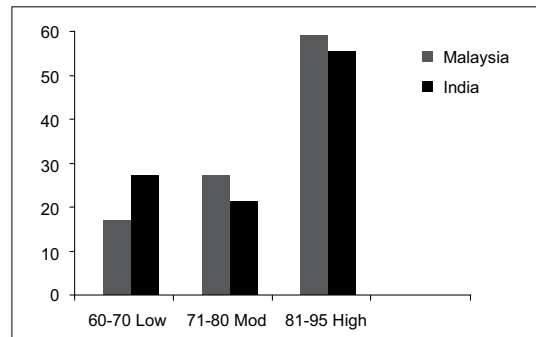


Figure 1: Caregivers' distribution by the BAS score

Appreciated for caring

28% of the Malaysian caregivers felt appreciated by their relatives for taking care of the patient in comparison to 22% in India.

Well-being

A majority, (56%), in India felt frustrated with the slow improvement of the patient compared to 30% of the caregivers in Malaysia. 54% in India felt that their workload has increased because of their relatives' illness compared to 32% in Malaysia. 44% of Indian caregivers felt that they need to temporarily separate from the patient in contrast only 24% of the caregivers in Malaysia. Surprisingly, 40% of the caregivers in Malaysia compared to 14% in India felt that there is no solution to their problems.

Caregivers' health

A vast majority (66%) of caregivers in India compared to 40% in Malaysia felt depressed and anxious because of the patient's illness. To support this variable, majority (58%) of the caregivers in India had sleep difficulties compared to 34% in Malaysia.

Caregiver's perception of burden

In this study, the scores of the caregivers were distributed in three ranges: from 60 to 70 (low), 71 to 80 (moderate), and 81 to 95 (high) [Figure 1]. In Malaysia, the least score on BAS was 61 and maximum score was 94. In India the least score was 62 and maximum score was 92, on the BAS. On combining, the scores showed that

- 42% of the caregivers in Malaysia, while 46% of the

caregivers in India had low to moderate perception of burden with a BAS score ranging from 60 to 80.

- 58% of the caregivers in Malaysia, while 54% of the caregivers in India had high perception of burden with a BAS score ranging from 81 to 95.

DISCUSSION

Schizophrenia is a chronic disease associated with a significant and long-lasting health, social, and financial burden, not only for the patient but also for families, other caregivers, and the wider society.^[14] Both caring of family members and receiving care are a major variable of family functioning; however, schizophrenia tends to alter this variable. Care giving becomes one way where the patient only receives and is unable to give.

Schene *et al.*^[15] have implicated some of the problems associated with care giving which are experienced negatively by the relatives which include strained home atmosphere; quarrels caused by the patient; guarding from patient committing dangerous acts, self-inflicted injury, and taking illegal drugs; ensuring that the patient got enough sleep; worrying about the patient's safety; urging the patient to take care of himself; urging the patient to eat enough; urging the patient to undertake activities; urging the patient to wake up in the morning; worrying about how the patient would manage financially if relative no longer help; and worrying about patient's future and about own future.

The aim of this study was to examine the level of perceived burden of the Malaysian and Indian families caring for a relative with schizophrenia using a BAS.

100 patients diagnosed with schizophrenia by a psychiatrist and their caregivers were studied in two different countries, namely India and Malaysia. Although there is not much cultural differences between the two countries it is intended to see if there is any variation in the burden of caregivers.

The mean level of perceived burden of the Malaysian caregivers' caring for a relative was higher (mean=80.46) compared to the Indian caregiver (mean=78.30), significant ($t=1.34$, $df=98$ $P<0.10$).

Variables that might have influenced the Malaysian caregivers are as follows.

- Age of the patient- The mean age of patient in Malaysia was 38 years while in India was 43. The impact of schizophrenia can be devastating particularly in younger patients as it means loss of productivity.
- Family support- The caregivers in India received better family support compared to the Malaysian

caregivers ($t=3.90$, $P<0.005$).

- Marital relationship- The Indian caregivers had a better marital and sexual relationship with their spouses (patient) as compared to the Malaysian caregivers, ($t=6.72$, $P<0.005$).
- Medical services- Caregivers in India were more (mean=2.82) satisfied with the medical services provided to them compared to Malaysian caregivers (mean=2.0). ($t=6.38$, $P<0.005$). Lay beliefs about schizophrenia may serve different functions for different ethno-cultural groups, which have an influence on help-seeking behavior. Malaysians tend to favor social-environmental explanations for schizophrenia. Specifically, Malay participants more strongly agreed that schizophrenia has a social cause, that treatment should affect changes at a societal level, that schizophrenic behavior is sinful, and that mental hospitals do not provide effective treatments.^[16]
- It is not that the Indians do not believe in lay beliefs. Pai and Kapur^[17] observed that fatalism and problem solving were the two most used mechanisms of coping. Generally, Indians are fatalistic and usually look for divine interventions in a crisis.
- Although statistically significant, there was not much difference in the mean on the BAS between the Malaysian caregivers' perception and the Indian caregivers'. The variables that could explain the Indian caregivers' perception of burden are as follows.
- Financial burden- It appears that the Indian relatives had severe financial difficulties compared to the Malaysian families. ($t=2.34$, $P<0.01$). The caregivers in Malaysia earned on an average of RM 1500 per month compared to Indian caregivers who earned a meager RM 1000 per month. Malaysian caregivers were comparatively better financially compared to their Indian counterpart. Longer the illness higher the financial burden the mean duration of illness was 11 years for Malaysia and 17 years for India. Schizophrenia is an expensive illness to treat even in developing countries.^[14] Schizophrenia imposes a disproportionately large economic burden due to expenditures for hospitalization, treatment and rehabilitation, and lost productivity.^[18] However, Mory *et al.*^[19] reported that although most spouses for patients with psychiatric disorders experience illness related financial disadvantages, these costs were usually not considered as serious problem or as burdensome.^[20] Based on a subjective hierarchy of burdens financial problems can be regarded as less important for spouses of patients with mental illness.
- Stigma-36% caregivers in India compared to 30% of the caregivers in Malaysia felt that their relative's illness prevented them from having satisfying relationship with friends. One of the reasons for this

could be because of stigma associated with mental illness. Mitigating effects of stigma are a priority for mental health policy, especially for schizophrenia.^[21]

- Well being- Indian caregivers were more frustrated compared to the Malaysian caregivers because of the slow improvement of the patient. ($t=1.75, P<0.05$). This could be explained by the fact that the average duration of illness was 17 years compared to only 9 years for Malaysia. This frustration could be the reason why the Indian caregivers felt depressed and anxious because of the patient's illness. It was found that the Malaysian caregivers were not too anxious as compared to the Indian caregivers ($t=2.97, df<0.005$). 40% of the caregivers in Malaysia compared to 44% in India felt that they need to temporarily separate from the patient.

Caregiver in both countries could benefit from various community-based programs such as removing stigma associated with mental illness and provision of better mental health facilities. Family education programs should help caregivers to improve their coping strategies. Therapy solutions must address negative symptoms just as much as positive symptoms, as these especially impact caregivers. Intensified community-based care can reduce burden, but provision alone is not sufficient. Psychiatrists and caregivers should motivate patients to take advantage of such offers.^[21]

In order to effectively work on long-standing unfavourable patterns of stress response, family interventions should be long term and targeted to vulnerable caregivers who could be identified by virtue of their personality traits.^[22] Family education programs should help caregivers to improve their coping strategies. Intensified community based care can reduce burden.^[23]

The implication of this study is it helped identify different variables that influenced the caregivers' perception in two different countries with almost similar culture and beliefs. Although the Indian caregivers perceived difficulties in several areas such as finance, family relationship, well-being and health, they still perceived burden to be lesser compared to Malaysian counterpart. Could this be answer by the earlier quotation by Pai and Kapur^[17] that "Indians are fatalistic and usually look for divine interventions in crisis."

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