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CAREGIVERS IN SCHIZOPHRENIA:
A CROSS CULTURAL PERSPECTIVE

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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. (Brady, N., & McCain, G.C, 2004).

The caregivers have to deal with patients’ symptoms, and help patients in activities of daily living.(Lueboonthavatchai, P and Lueboonthavatchai, O, 2006). Caregivers look at several stressors including financial, family structure, and physical health demands amongst many others. (Nehra et al., 2005). Care giving could be stressful. Caregivers of persons with schizophrenia and other disorders experience high levels of burden. (Caqueo-Urizar A and Gutierrez-Maldonado J, 2006).

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. (Awad and Voruganti, 2008). According to Dean et al, (2006), the relationship between coping styles and perceived burden of care is complex because caregivers subjectively report ‘burden’. The burden of care givers is more dependent on their
appraisal of the condition of their patients rather than the actual illness. (Creado et al, 2006).

Burden of care could be perceived differently in different cultures. Lin and Kleinman (1998), 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 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. (Yip, 2006)

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. (Sahar et al, 2003). 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). (Rossier et al., 2005).

The assessment of Years Lived with Disability (YLD) and non fatal burden in Malaysia shows that 21% of the burden was contributed by mental disorders both in men and women. (MOH, 2004).

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 cultural determinant factors that contribute to the caregivers burden and assesses the differences in the burden of care in different countries using the same assessment schedule.

The goals for this study is to examine the demographic aspects of the caregivers, the levels of perceived burden of caring for a relative, and the cultural determinants that contribute to the burden of care.

Methods

Study site: The study site includes Malaysia as well as Malaysia.

Study design: Questionnaire

Sample selection: 50 cases from Malaysia and India were selected. In all 100 patients and their primary caregivers were selected from undergraduate medical students involved in data collection. The study was conducted separately.

Criteria: The inclusion criteria for the study was the diagnosis of schizophrenia, the patient to be under 60 years of age, the primary caregiver was either the wife, adult daughter or daughter in law. Patients with co-morbid medical conditions were included and patients who were not related to the patient and had difficulty in comprehending English were excluded.