



Lived Experiences of Family Caregivers Caring for Members with Chronic Schizophrenia at Home in Kelantan, Malaysia

Ms. Lim Phaik Hooi

Adult Nursing

Advisory Committee

Examiners Committee

Chairman
Asst. Prof. Dr. Wanida Sathasongkol

Asst. Prof. Dr. Wanida Sathasongkol

Lim Phaik Hooi

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Author Ms. Lim Phaik Hooi
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Abstract

This study was designed to explore experiences of family caregivers caring for members with chronic schizophrenia at home in Kelantan, Malaysia, using the phenomenological approach. The objectives of the study were to: (1) describe the meaning of 'caring', (2) describe the caring experiences, (3) identify the impacts of caring experienced by family caregivers, and (5) identify the needs of family caregivers when caring. The participants of this study consisted of 10 primary family caregivers. Potential participants who accompany care-recipient for follow-up care for acute symptoms at the Outpatient Psychiatric-Mental Health Clinic, University Sains Hospital were approached for permission to participate in the study.

Three types of data collection tools were Demographic Data Record Form, Observation Guide, and Interview Guide. Participants were interviewed at their homes, using in-depth interviews, lasting about 60-90 minutes, in 2-3 sessions interviews. Data were analysed by descriptive analysis and through the process of hermeneutic interpretation, using the guideline of Giorgi's method. The three main themes emerged as meaning of caring were caring for the well-being, responsibility as a parent, and being a burden. The family caregivers reflected their caring experiences in five themes as managing the illness, providing daily care, changes of feelings during care, future concern, and coping experiences. Negative impacts of caring identified were being burdened, being ahsamed, physical ill health, loss of job, feared by other family members, while positive impacts were gaining knowledge and expereinces, and self-fulfillment. They described their needs as keep themselves healthy, requiring support resources, financial support, temporary replacement, inner strength, expression of feelings, and information needs.

The findings of this study enabled psychiatric-mental health nurses and others to

understand better how caregivers construct their views on caring, how they feel and perceived their caring experiences, their needs and impact, thus able to assist them in their role as caregivers more effectively. Nurses should encourage use of Malay culture and beliefs when assisting and promoting better care for Malay caregivers. It's purposive sampling reduced the generalizability of the findings, and thus should be applied with caution in other settings, bearing in mind cultural differences, duration of caring and personal characteristic of caregivers. There should be a study to explore religious practices as coping strategies by family caregivers, and to cover other chronic mental illness as well. Finally, a participatory action research may be used to develop a model of care to assist family caregivers in their caring.