Psychological Outcomes of Family Caregivers of Mental Illness Patients

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Abstract: Previous research shows considerable variability in the impact of caring on family caregivers of mental illness but the multidimensional experience of caring remains unexplained. The study aimed to identify family experiences of caring in a developing country. There were 154 family caregivers recruited for the survey. In addition, twenty-four respondents participated in semi-structured interviews about their personal caring experiences. This study found that majority of caregivers was women and aged less than 60 years. More than half of the participants were found to be psychologically distressed. Consistent with the stress-coping model, only caregivers' negative appraisal was a strong predictor of psychological distress and accounted for a substantial proportion of its variance. Positive appraisal, ethnicity and residential area did not predict psychological distress. Interview findings related to the coping styles and social supports of the family caregivers. The implications for mental health services are that many of the caregivers need help in their own right. Not only the person with mental illness who should be targeted for evaluation but the differences in caregivers' appraisal on their caring role taken into consideration.

Key words: Family caregivers · Psychological distress · Mental illness

INTRODUCTION

Since 1990s there has been a decrease in the number of patients in Malaysian institution-based mental health care. One of the salient impacts of deinstitutionalization is that an increasing number of families involved in taking care of persons with severe mental illness [1]. Many studies found that the family caregivers are unprepared to provide ongoing care and support demanded by their mentally ill patients and these caregivers were also burdened to care especially in societies that provide limited resources for mental health patients [2-6]. However, the conceptualization of burden has proved elusive and it is frequently criticized for being broad pessimistic [7]. Therefore, many researchers suggested that caregivers to mentally ill patients do not necessarily experienced burden [8-10]. Previous research found 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 agent of rehabilitation process in the

community mental health services [11, 12]. It is more exacerbate when many researchers focused only on the negative aspects and not tap on the positive aspects of caring [13-15].

Moreover, the experience of caring for patient with mental illness has become more complex especially in developing countries [14]. In Malaysia, the families choose to look after their ill members at home and view hospital as the last resort [16]. However, the situation is quite different with mental illness, where families prefer that their patient be admitted to an institution rather than receive care at home. This is to conceal the fact that their patient has a mental illness and to avoid social stigma [16, 17]. The meaning of mental illness is often misinterpreted in the Malaysian society. For centuries, it has been seen as possession by evil spirits, moral weakness or punishment from a higher being or god [18]. Those suffering from mental illness are commonly perceived as restless, violent and unpredictable [19]. The prevalence of burden experienced by Malaysian

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caregivers is extensive with 40% of the caregivers experience severe subjective burden and 35.6% experience objective burden [20]. Prevalence also occurs within the traditional Chinese families where they perceived mental illness as a punishment for misleads done by individuals of their families [17]. Consequently, some people often stereotypes schizophrenia as dangerous, violent and beyond professional help [21]. In fact, the society treats mental illness as a family problem rather than a societal problem [4, 23]. At present there are lack of services and facilities in the health systems that offer social services to patients and their families in Malaysia [23]. These barriers in the social services are making the caring experience to be more stressful and taxing. Therefore this paper aims to identify the family's experience of caring for mental illness patients in Malaysia. This paper also intended to examine the multi-dimensional experiences of caregivers by investigating into different areas such as ethnicity, gender, age and relationship status as predictors for caregivers' psychological distress under the stress-coping paradigm by Lazarus and Folkman [24].

MATERIAL AND METHOD

This study used a mixed-method research design. The quantitative method was used to identify the correlation of stress amongst the family caregivers. Meanwhile, the qualitative study was to describe the cognitive appraisal and adaptation of psychological distress. The participants in this study were Malay, Chinese and Indian caregivers, living in the rural and urban area. They were those who sought the community mental health treatments for their patients in three community clinics in the Northern states of Peninsular Malaysia as based on the National Mental Health Registry [25]. Additional inclusion criteria for recruitment of participants included: (1) aged above 18 years old, (2) main caregivers, (3) more than 6 months caring for patients and (4) possess the ability to express themselves clearly in Malay and English languages.

In order to measure the family's experience of caring, three instruments were used in this study. These instruments were the Experience of Caring Inventory (ECI) [7], the Life Skills Profile-39 [26] and the General Health Questionnaire-12 [27]. The Qualitative Interview Guide was a 14-question, semi-structured tool used to identify caregivers' experiences of caring. This study was given ethical clearance upon commencement. Out of the 200 family caregivers that participated in the survey, 154

completed the survey accordingly. All the data in this study was analyze using concurrent mixed methods data analysis [28, 29]. The SPSS software version 14 was used to organize all the survey data while all the interviews data was organized using the NVivo software version 8.

RESULTS

Characteristics of Caregivers: There were 154 caregivers that participated with almost 80% of them were female. Most participants (70.1%) were aged 41-60 years; the vast majority was Malay (88%) and dwelling in the rural area; most (88%) were married. More than half of caregivers have had primary level education and less than half were employed especially in the rural area. The relationship of caregivers to patients was: parents, 58.4%; spouse, 24% and siblings, 17.5%. Only 57.1% of the household income was more RM500 per month and over two-third were having more than four family members within a household. In association between caregiver's background and different area showed that two-third of Malays live in the rural area; urban caregivers have more income; and rural caregivers have larger household size. According to the test of differences using the Chi Square test, only ethnic groups (χ^2=43.55, p<0.005), relationship status (χ^2=13.35, p<0.005), household income (χ^2=19.55, p<0.005) and household size (χ^2=6.35, p<0.005) were significantly different between urban and rural areas. Yet, there were no significant difference found between ethnicity and caregivers' background except for household income (χ^2=8.59, p<0.005) and household size (χ^2=13.74, p<0.005).

Caregivers' Negative Appraisal of Caring: The results of the multivariate analysis of predictors are shown in Table 1. Statistically significant predictor for caregivers' appraisal was negatively associated with patient's characteristics. It suggests that caregivers appraised negatively when their patients' had poor life skills, no jobs and of younger age group. All variables were accounted for 58.8% of the variance in the total ECI negative scores.

Caregivers' Positive Appraisal of Caring: Four predictors were significantly associated with the total ECI positive scores. These predictors were living in rural area household with income more than RM800 per month, patient's who is married and good life skills (Table 2). All these variables accounted for 29.3% of the variance in the total ECI positive scores.

Table 1: Multivariate model for caregiver's negative appraisal of caring

Predictor Variables	B	Std. Error	Beta	T	p	95% Confidence Interval for B	
(Constant)	562.70	42.30		13.30	0.001	479.11	646.29
LSP-39 Score	-98.24	8.8	-0.63	-11.16	0.001	-115.64	-80.84
Age of patient	-0.59	0.18	-0.18	-3.38	0.001	-0.94	-0.25
Patient's unemployed	12.72	3.50	0.20	3.64	0.001	5.81	19.64

Adjusted R Square = 0.588

Table 2: Multivariate model for caregiver's positive appraisal of caring

Predictor Variables	B	Std. Error	Beta	t	p	95% Confidence Interval for B	
(Constant)	-124.09	21.88		-5.67	0.000	-167.33	-80.85
LSP-39 Score	32.38	4.59	0.49	7.06	0.001	23.32	41.44
Rural area of living	-7.88	2.44	-0.26	-3.23	0.002	-12.70	-3.05
Household Income	1.32	0.89	0.11	1.48	0.140	-0.44	3.07
Patient who is married	3.19	1.57	0.16	2.03	0.044	0.08	6.30

Adjusted R Square = 0.293

Table 3: Model prediction for the caregiver's psychological distress

Model		B	Std. Error	Beta	t	p	95% Confidence Interval for B	
1	(Constant)	25.389	2.126		11.941	0.000	21.187	29.590
	Age of patient	-0.214	0.055	-0.302	-3.886	0.000	-0.323	-0.105
Adjusted R Square = 0.085								
2	(Constant)	22.511	2.332		9.655	0.000	17.904	27.118
	Age of patient	-0.202	0.054	-0.285	-3.725	0.000	-0.309	-0.095
	Patient's Employment status	2.904	1.060	0.209	2.739	0.007	0.809	4.998
Adjusted R Square = 0.123								
3	(Constant)	25.222	2.668		9.453	0.000	19.950	30.495
	Age of patient	-0.223	0.055	-0.314	-4.079	0.000	-0.330	-0.115
	Patient's Employment status	20.768	1.051	0.200	2.633	0.009	0.691	4.846
	Household income per Month	-0.970	0.479	-0.156	-2.025	0.045	-1.916	-0.023
Adjusted R Square = 0.141								
4	(Constant)	88.420	12.208		7.243	0.000	64.294	112.546
	Age of patient	-0.161	0.052	-0.227	-3.122	0.002	-0.263	-0.059
	Patient's Employment status	1.227	1.010	.089	1.215	0.226	-0.769	3.223
	Household income per Month	-0.711	0.443	-0.114	-1.605	0.111	-1.587	0.165
	Total LSP-39 score	-13.510	2.556	-0.396	-5.285	0.000	-18.562	-8.458
Adjusted R Square = 0.273								
5	(Constant)	33.115	17.007		1.947	0.053	-0.498	66.729
	Age of patient	-0.093	0.050	-0.132	-1.879	0.062	-0.191	0.005
	Patient's Employment status	-0.242	0.976	-0.017	-.248	0.805	-2.171	1.687
	Household income per Month	-0.656	0.421	-0.105	-1.561	0.121	-1.488	0.175
	Total LSP-39 score	-4.629	3.302	-0.136	-1.402	0.163	-11.155	1.897
	Total ECI negative	0.113	0.022	0.522	5.088	0.000	0.069	0.157
	Total ECI positive	0.070	0.039	0.136	1.799	0.074	-0.007	0.147

Adjusted R Square = 0.379

Caregivers' Psychological Distress: According to the GHQ-12, almost 55.3% of the caregivers' experiences psychologically distress. The results of the stepwise regression analysis predicting psychological distress were shown in Table 3. All sample characteristics which were significant through the Pearson product-moment correlation coefficient were entered into the multiple regressions analysis. In the first step, the age of patients became the first model, accounting for 8.5% of the variance. Next the patient employment status became the second model, adding 3.8% to the variance of the first model. The family income per month became the third

model and all these sample variables contributed 14.1% of the total variance in the first block. Caregiver, who has younger patients, did not work and those with lower family income per month reported higher levels of psychological distress.

In the second step, the patient's life skills profile (regarded as stressor) in this study was entered as a block. While only age of patient remained significant but the patient unemployment status and the family income per month became non-significant. The patient life skills became the fourth model. Caregiver who perceived patient's with lower life skills profile emerged as significant predictors of psychological distress. This second block accounted for 27.3% of the variance. Finally, in the third step, the block of the negative and positive ECI was entered. Only the ECI negative scores emerged as a significant predictor of psychological distress. The ECI negative contributed almost 10% of the total variance.

Coping Strategies: The family caregivers had developed a wide range of strategies to cope with the long-term caring situation. There were five coping styles such as practical coping, emotional coping, 'detachment', cultural coping, hope and faith. Hope and cultural copings were the two most important strategies identified. Caregivers used hope to motivate them to continue with the caring. Caregivers took practical action by sharing their problems with other people especially with the mental health professionals because they believed it would help them solve the problems of their patients. Some of the caregivers used positive and constructive thinking to cope with their negative emotions. They believed that they had commitment and responsibility towards their patient so that they need to stay positive in their mind. Caregivers were also used 'detachment' by thinking of other matters instead of thinking about their patients.

Besides, caregivers accounted of using cultural copings which include religious coping and traditional coping when dealing with mental illness. Both coping strategies had been used because of their cultural beliefs and available resources in the community. Some of the caregivers seek alternative treatments for patients, for instance, a Malay caregiver in rural area described that she used *bomoh* (traditional healer) to treat her son because she assumed spirit possessions rather than mental disease especially in the early stage of the mental health. Likewise, the majority of Chinese caregivers also used traditional coping to deal with mental illness. An Indian caregiver also admitted that she used an ayurvedic treatment to treat her patient's mental illness. Some of the

caregivers also reported that they have faith in God and it's their destiny to look after patients with mental illness. They believed it is God's will that they need to endeavor their life by worshiping to God and be better believers.

Social Supports: The caregivers experienced different level of supports from their surroundings. Basically they received support from their family members, close friends and mental health professionals. For some caregivers they had support from their family especially with practical and financial assistants. The practical supports included help to care, able to help with housework and take the patient for recreational and social activities. Due to their financial problems, financial support from their children was really important especially when they were unable to work and needed to focus on their caring roles. Caregivers also mentioned that their patients received social supports from the community. For instance, a husband said, "my wife's friends who know about her illness always motivate her to be strong and fight for her freedom". Moreover, caregivers felt supported when they got involved in the family support group. They found that the support group is important to keep them motivated to care for their patient. It was considered a good platform for caregivers to share and learn about their caring experiences. Caregivers also admitted receiving informational supports about patients' mental illness when they were using the community mental health services.

DISCUSSION AND CONCLUSION

This study on the experience of caring for a person diagnosed with schizophrenia is probably one of the mixed methods research that have been completed in Malaysia. It is also unusual in two other aspects. Firstly, it is a comparison between three different ethnic groups, Malay, Chinese and Indian. Secondly, the data were collected in two different areas, urban and rural. However, due to the fact that the data were selected from two community clinics in two states, it is inappropriate to generalize the findings as representing the country as a whole. One important contribution is that, although in terms of socio-demographic variables and mental illness condition the sample is comparable to other recent study of caring burden in semi-urban area in Kelantan [20] (eastern state of Peninsular Malaysia). Samples of caregivers in urban areas are comparative with the samples of the study conducted in Johor [17] (southern state of Peninsular Malaysia) which focused on Chinese family experiences of caring mental illness patients.

The multivariate analysis of the survey data found that the patient's social life skill, measured by the LSP, was the strongest predictor of the caregiver's positive appraisal of caring and also of negative appraisal. However, the patient's difficult behavior, as measured by the ECI, did not directly influence the caregiver's negative appraisals [7]. Only the negative appraisal of caring predicted the caregiver's psychological distress and none of the demographic factors and positive appraisal of caring. In other words, caregivers who negatively appraised their experience of caring were more likely to be distressed regardless of whether they have positive experiences or their demographic background. The negative appraisal of caring was determined by the service user's characteristics such as younger, unemployed and poor life skills, while the caregiver's positive appraisal of caring was predicted by the caregiver's characteristics including living in an urban area and a family's monthly income of more than RM800; and the service user's characteristics such as married and has good life skills.

The interview findings showed that caregivers viewed their experience positively when they continuously received social support from mental health professionals and their family members as well as their closest friends. Positive appraisals of caring were also related to caregivers who used active coping strategies including practical coping, emotional coping, detachment, cultural/religious coping, faith and hope. In contrast, caregivers had a negative experience of caring when they were recurrently constrained by their personal and environmental problems. Caregivers reported personal constraints including the emotional and psychosocial impacts of caring. The majority of the caregivers acknowledged being worried and distressed because of their patients' poor condition, which included positive and/or negative symptoms as well as difficult behavior. Caregivers who were parents and older tend to be more worried about their patients' future, especially after they die, as they were concerned about who would take over their responsibility. Many caregivers also reported being disrupted by their caring roles and experienced financial burden. In addition, caregivers also highlighted environmental constraints such as social stigma and the limited resources in the community. In spite of the constraints of caring, caregivers who used active coping styles were less likely to be distressed than caregivers who used passive coping.

The findings have consistently show that caregivers have two essential needs: skills to cope with distress and to support themselves morally and financially. These two factors were considered as mediators in the stress and coping framework [7, 23]. Reflecting the impact of deinstitutionalization to the caregiver's psychological distress, the mental health professionals should aim to empower the family caregivers and acknowledge caregivers' needs.

In conclusion, more than half of caregivers in this study identified to be psychologically distressed and they negatively appraised their experiences of caring. However, the interview findings proved that the family caregivers were positively appraised their caring when using the active coping strategies and received adequate support from their support systems. All the caregivers' experiences provide an overview of multidimensional aspects of caring, which specifies the essential needs of the Malaysian families. The positive and negative experiences of caring promote the family diversity that highlights different needs of different groups with different levels of stress. Mental heath profesional should identify that the family caregivers need help in their own right. Not only the person with mental illness who should be targeted for evaluation but the differences in caregivers' appraisal on their caring role taken into consideration.

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