

Quality of life of caregivers of patients with psychiatric illness in Penang.

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Abstract

Introduction: There has been a shift from institutional to community based care for patients with mental illnesses. With increasing prevalence of psychiatric illness, more patients are being treated in the community which can affect the quality of life of caregivers.

Objective: To determine the quality of life of caregivers of patients with psychiatric illness on follow up in public hospitals providing outpatient psychiatric services in Penang, Malaysia.

Methodology: This cross-sectional study was conducted 221 randomly recruited patients and their caregivers. These caregivers were interviewed face-to-face using WHOQOL-BREF questionnaire to evaluate their quality of life.

Results: Caregiver's single, widowed and divorced status (ANOVA=3.09, p=0.029), lower level of education (ANOVA=4.18, p-value 0.017) and Chinese race (ANOVA=6.98, p-value<0.001) were significantly associated with the poor QOL. Whereas, the patient's Chinese race (ANOVA=10.17, p-value<0.0001) and profession (ANOVA=3.15, p-value<0.002) were significantly associated with the caregiver's quality of life.

Conclusion: It is important for health care providers and policy makers to understand the factors that influence the quality of life of caregivers considering more patients with psychiatric illness are being cared for in the community.

Keywords: Psychiatric, Adaptations, Stress.

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Introduction

Psychiatric illness is increasingly becoming a major public health problem [1-3]. In Malaysia, the prevalence of psychiatric illness has shown an increasing trend: the prevalence has increased from a mere 10% in the last decade to 30% in 2015 according to the National Health and Morbidity Survey 2015 [4]. This is due to the recognition of mental disorders in the community and increased awareness among fellow Malaysians. There are also more correctly diagnosed mental disorders among Malaysians [4].

There has been a shift in the care of psychiatric patients in institutions to home care with larger involvement of community than the conventional in-hospital treatment. This may inadvertently lead to increased burden on the family members and relatives who are caregiving of psychiatric patients.

Caregivers are defined as persons caring for patients, most of whom are relatives of the patients [5-7]. Family members are the pillars of strength in their patients' lives. They provide practical help, personal care and emotional support to the patients. Caregiving is difficult and demanding and can affect the caregiver's physical and emotional health resulting in financial and social constraints [8]. The severity of caregiving burden has been linked to patient's disease, meeting the patient's needs, patient's lower global functioning and quality of life (QOL) [8].

QOL, according to the World Health Organization's (WHO) definition is an individual's perception of his or her own situation. However, this concept has gone through more definition and redefinitions and different clinical, functional and social variables have been included. It is now the general consensus to perceive quality of life more holistically, to include the satisfaction with life, and satisfaction with its particular domains. It is now deemed acceptable to view quality of life as a fulfillment of dimensions which are sensitive to adaptations [9-11].

Studies have often shown that caregivers of patients of many diseases or ailment generally have lower QOL compared to non-caregivers [12-15].

Caregivers of patients with mental illnesses have reported lower QOL compared to non-caregivers and caregivers of patients with other chronic illnesses [16]. Caregivers of patients with mental illnesses have reported higher incidences of heartburn, headache, depression and anxiety, sleep difficulties, insomnia and the possibility of even leading to death [16-18]. Caregivers have also documented more stress, psychological issues, social isolation and family conflicts [19]. Three factors have been found to significantly impact the QOL of the caregivers - caregiving situations, caregiving factors and environmental factors. Caregiving situations are variables pertaining to the disease. Caregiving factors are variables defining the caregivers

and environmental factors include support from family members and the health care system.

Lack of peer support, lower self-perceived QOL, caregiving for a patient with psychosis and being female have been shown to be predictors of poor QOL among caregivers [17]. Chinese caregivers have been found to have significantly higher caregiving burden and distress compared to other races [19,20]. Presence of informal help has been shown to reduce the distress experienced by primary caregivers, although the presence of formal help does not alleviate caregiving stress [19]. Advanced age, being a parent and increasing number of hours in contact with patient have also been linked to higher caregiving burden [21,22]. Caregiver's higher level of education predicts better caregivers' QOL [17,23], whereas, being unmarried and certain types of occupation have been shown to be predictors of poor QOL among caregivers [17].

Patient's variables too influence the QOL of caregivers. Patients with psychosis, increasing age, gender, longer duration of disease, longer duration of treatment, non-compliance with medication, two or more admissions of the patients, and deteriorating physical health and dementia are factors that have been shown to be associated with poor caregiver's QOL [19,24].

Objective

The objective of this study was to determine the quality of life of the caregivers of patients with psychiatric illness on follow up in public hospitals providing outpatient psychiatric services in Penang, Malaysia.

Methods

Study design

This cross-sectional study conducted in two public hospitals providing psychiatric outpatient services in Penang, Malaysia from June to December 2016.

Setting

There are two public hospitals which provide psychiatric services in Penang, Malaysia, i.e., Penang Hospital on the island and Bukit Mertajam Hospital on the mainland. Penang Hospital is a 1090-bedded hospital located in the Penang Island while Bukit Mertajam Hospital is a 250-bedded hospital.

Sample

The target population were the primary caregivers of patients on psychiatric follow up in these two hospitals. STATA 13 software was used to calculate the sample size. The sample size was calculated based on power of 90%, significance level of 5%, using the estimated QOL of caregivers at 70.0. The mean QOL score of a study by ZamZam et al. [20] in Malaysia showed that the mean QOL of caregivers in Malaysian families was 63.7 with a standard deviation (SD) of 15. This mean score was used as the basis for the calculation of sample size. The estimated QOL score was 70.0, based on the average QOL of different studies around the world [20,25,26]. The total sample size needed was 172 caregivers. Considering the possibility of 25% non-response rate and possibility of incomplete data the

total number of 221 was taken as the minimum sample size. A sample frame consisting of 472 patients from Penang Hospital and Bukit Mertajam Hospital based on the number of outpatients in the last two months were used to randomly select 221 patients with mental illness. To avoid biases, the inclusion criteria were: caregivers of patients with mental illness diagnosed based on ICD-10 classification diagnosis of mental illness (Mental and Behavioural Disorders), caregivers of patients attending the outpatients clinics in Bukit Mertajam Hospital, and Penang Hospital.

Tool

The caregivers were interviewed face-to-face by interviewers who were trained using a standardized training manual. A 42-question questionnaire was used. The questionnaire was further subdivided into three sections. The first section was the demographic profile of the caregivers which included age, gender, marital status, highest level of education obtained, race, income, distance of residence from the hospital and occupation. The second section included questions on the patient's demographic profile. The questions asked in this section were the patient's gender, age, marital status, highest education, race, diagnosis and occupation. The data for second section was collected from the caregivers with permission from the patient. The third section was the WHOQOL-BREF questionnaire. This is the World Health Organisation Quality of Life Questionnaire-short version. It is a generic instrument which is the short version of the WHOQOL-100. The four domains of the WHOQOL-BREF are physical health, psychological, social relationships and environment [27]. The WHOQOL-BREF has been shown to have good internal consistency, discriminate validity, criterion validity and test-retest reliability. The Cronbach's alpha internal consistency was shown to range between 0.47 and 0.78 [28]. The Cronbach alpha scores for the physical domain between 0.64 and 0.80, in the psychological domain 0.64, 0.65 in the social domain, and 0.73 in the environmental domain. The WHOQOL-BREF questionnaire has been shown to have good test-retest reliability. The intra-class correlation coefficient (ICC) ranged from 0.49 to 0.88. The Pearson's correlation showed that the WHOQOL-BREF has significant correlation between current health status and the domains. The scores were 0.65 for physical domain, 0.44 for psychological domain, 0.32 for social domain, and 0.45 for environmental domain. It is also shown to fare fairly well on the discriminant validity and construct validity [29].

Ethics

Because this study involved a vulnerable group the interviewers abided by the Belmont Principle and showed respect to the caregivers and patients and ensured that the study was beneficial to both caregivers and patients. The confidentiality of the participants is ensured at all times. Informed consent was obtained from the caregivers and patients. The proposal was submitted to the Medical Research Ethics Committee (MREC) and the study was approved by MREC (NMRR-16-193-29392 (IIR)).

Analysis

The analysis was done using STATA 13 Software. The data is represented descriptively using tables and cross-tabulations. Mean scores of QOL are compared across the variables using t-test and ANOVA. Bonferoni was applied as post-hoc analysis. Simple linear regression and multivariate linear regression were used to determine significant variables. A p-value of 0.05 is taken as cut-off point for statistical significance. A p-value of 0.20 was used to choose the variables obtained from simple linear regression for multivariate analysis.

Table 1 shows the baseline profile of the respondents. Most of the caregivers were in the age group 41 to 60 years old (48.1%), women (65.2%), married (81.8%), highest level of education up to secondary school (71.7%) and of the Chinese race (44.9%).

Table 1 also shows the baseline profile of the patients. Most of the patients were less than 20 years old (51.3%), men (51.3%), single (63.6%), highest level of education up to secondary school (42.5%) and of Chinese ethnicity (n=84, 44.9%).

Table 1. Baseline profile of respondents.

Variables	Frequency/Percentage	Frequency/Percentage
	Caregiver (n%)	Patient (n%)
Age		
Less than 20 years old	0	96 (51.3)
21 to 40 years old	82 (43.9)	35 (18.7)
41 to 60 years old	90 (48.1)	25 (13.4)
61 to 80 years old	15 (8.0)	28 (15.0)
Above 80 years	0	3 (1.6)
Gender		
Men	65 (34.8)	96 (51.3)
Women	122 (65.2)	91 (48.7)
Marital status		
Married	153 (81.8)	49 (26.2)
Single	21 (11.2)	119 (63.6)
Widow/er	7 (3.7)	17 (9.1)
Divorced	6 (3.2)	2 (1.1)
Education		
Illiterate	0	6 (3.2)
No formal education	0	25 (13.4)
Primary school	22 (12.0)	71 (38.2)
Secondary school	132 (71.7)	79 (42.5)
Tertiary education	30 (16.3)	5 (2.7)
Race		
Malay	74 (39.6)	74 (39.6)
Chinese	84 (44.9)	84 (44.9)
Indian	28 (15.0)	29 (15.5)
Others	1 (0.5)	0
Occupation		
Professionals	15 (8.0)	4 (2.9)
Non-Professionals	106 (56.7)	21 (11.2)
Housewife/Unemployed	66 (35.3)	162 (86.6)
Income		
Less than RM2500	153 (81.8)	N/A
RM2500-RM5000	30 (16.0)	N/A
RM5000-RM7500	1 (0.5)	N/A
More than RM7500	3 (1.6)	N/A
Mean distance from residence to hospital (km)	17.8 (SD17.258)	N/A

Table 2. Quality of life scores of caregivers.

	Mean	Standard deviation	Min	Max
Overall QOL	64.9	14.4	10.3	98.9
Physical	67.4	15.2	10.7	100.0
Psychological	64.1	16.1	8.3	100.0
Social	67.2	17.1	8.3	100.0
Environmental	61.1	16.1	13.8	100.0

Table 2 shows the mean overall and the QOL scores for the different domains. The highest mean scores for the respondents were in the physical domain, followed by social, psychological domain and environmental domain.

As shown in Table 3, the difference in the mean QOL scores of the married (66.2), single (63.1), widowed (54.3) and divorced caregivers (53.6) was statistically significant (ANOVA=3.09, p=0.029). The mean QOL score of the caregivers with secondary school education is higher than those with primary school and this is statistically significant. (ANOVA=4.18, p-value 0.017) The mean QOL score of the caregivers who are Malay is higher than that of Chinese (ANOVA=6.98, p-value<0.001). The differences in other variables related to the caregivers were not statistically significant.

As shown in Table 3, the mean QOL score of the caregivers of Malay patients is statistically higher than the Chinese. (ANOVA=10.17, p-value<0.0001) The differences in the variables for patient's age (F=1.12, p-value=0.349), gender (t=-1.12, p-value=0.263), marital status (F=0.20, p-value=0.894), education (F=0.36, p-value=0.836) and patient's occupation (F=2.26, p-value=0.107) were not statistically significant.

The differences in the distance from the caregiver's home to the hospital were not statistically significant (p-value=0.594).

Table 4 show the results of multiple linear regressions for caregivers and patients. Chinese caregivers are associated with poorer QOL compared to other races (coefficient=-7.85, p-value=0.001). Similarly, caregivers of Chinese patients have poorer QOL compared to caregivers of patients of other races (coefficient=-9.76, p-value<0.001).

Discussion

The mean QOL score in this study is lower than that found in studies from China (84.0 & 87.2), Taiwan (87.6) and Hong Kong (79.6) [26,30]. This difference have been attributed to cultural differences, how the caregivers perceive their own well-being, expectation for the government to assume responsibility for reducing mental healthcare burden of the society- including having more financial resources, higher sense of freedom and better home environment [26,31]. The mean QOL scores of this study is almost similar to the study conducted in the National University Malaysia (UKM) Hospital, which was 63.7 [32] and another study in Sao Paulo, Brazil (63.0) among caregivers of patients with attention deficit hyperactivity disorder. The reason of similar QOL scores in the Brazil study and the Penang study is because of reduced contact social interaction [33]. However, the QOL of caregivers of patients with mental illness followed up in Penang Hospitals was much better than caregivers followed up

Table 3. The association of caregiver's and patient's baseline profile with the mean QOL score.

Variables	Mean Quality of Life score (95%CI)	T-test/ANOVA	Mean Quality of Life score (95%CI)	T-test/ ANOVA
		p-value (post hoc)		p-value (post hoc)
Caregivers		Patients		
Age		1.10/0.336		1.12/0.349
Less than 20 years old			65.51 (62.69-68.33)	
21 to 40 years old	66.56 (63.80-69.32)		65.89 (62.35-69.44)	
41 to 60 years old	64.12 (60.72-67.51)		60.95 (53.76-68.13)	
61 to 80 years old	61.48 (56.12-66.83)		64.28 (58.25-70.31)	
Above 80 years old			77.25 (64.15-90.34)	
Gender		0.8197/0.413		-4.2654
Men	66.16 (62.67-69.66)		63.83 (60.87-66.78)	
Women	64.35 (61.75-66.94)		66.19 (63.27-69.12)	
Marital status		3.09/0.029		0.20/0.894
Married	66.17 (63.94-68.40)		64.01 (59.41-68.61)	
Single	63.13 (56.81-69.45)		65.15 (62.71-67.58)	
Widow/er	54.33 (43.04-65.62)		65.90 (58.19-73.61)	
Divorced	53.55 (39.85-67.26)		70.68 (48.47-92.90)	
Education		4.18/0.017/(2)>(1)		0.36/0.836
Illiterate			67.10 (58.32-75.87)	
No formal education			65.41 (59.70-71.12)	
Primary school	57.41 (52.64-62.17)		64.82 (61.20-68.45)	
Secondary school	66.36 (63.98-68.75)		65.91 (63.16-68.66)	
Tertiary education	66.61 (61.36-71.85)		58.59 (44.58-72.80)	
Race		6.98/<0.0001(1)>(2)		10.17/<0.0001(1)>(2)*
Malay	70.00 (67.05-72.95)		70.01 (67.06-72.96)	
Chinese	60.05 (56.72-63.38)		60.16 (56.82-63.51)	
Indian	66.32 (62.56-70.08)		66.07 (62.41-69.74)	
Others	69.79			
Occupation		0.43/0.649		2.26/0.107
Professionals	68.11 (60.04-76.19)		57.13 (33.30-80.96)	
Non-Professionals	64.98 (62.08-67.89)		59.80 (52.35-67.25)	
Housewife/Unemployed	64.26 (61.12-67.39)		65.84 (63.72-67.96)	
Income		0.397		N/A
Less than RM2500	64.48 (62.24-66.73)		N/A	
RM2500-RM5000	66.69 (61.21-72.17)		N/A	
RM5000-RM7500	87.2		N/A	
More than RM 7500	65.54 (36.74-94.34)		N/A	

Table 4. Multiple linear regression showing the caregiver's and patients factors which associated with quality of life of caregivers.

Variables	Overall Quality of Life score (Mean score)	Coefficient (95%CI)	p-value
Caregiver's age	64.98	-0.08 (-0.28-0.13)	0.466
Caregiver's Marital status			
Married	66.17	0	
Single	63.13	-2.34 (-9.10-4.41)	0.494
Widow/er	54.33	-6.78 (-17.39-3.83)	0.209
Divorced	53.55	-9.33 (-20.49-1.82)	0.100
Caregiver's Education			
Primary school	57.41	0	
Secondary school	66.36	5.13 (-1.51-11.78)	0.129
Tertiary education	66.61	5.34 (-3.12-13.81)	0.215
Caregiver's Race			
Malay	70.00	0	
Chinese	60.05	-7.85 (-12.28-3.42)	0.001
Indian	66.32	-3.48 (-9.43-2.46)	0.249
Others	69.79	-0.68 (-26.88-25.51)	0.959
Patient's race			
Malay	70.01	0	
Chinese	60.16	-9.76 (-14.02; -5.50)	<0.001
Indian	66.07	-2.82 (-8.75-3.11)	0.349

in a hospital in India (58.4). The study in India was done among caregivers of obsessive-compulsive patients [25]. Studies have shown that caregivers of patients with obsessive compulsive disorders have lower QOL [34,35]. However, comparison cannot be made with this study as the caregivers are a set of caregivers of patients with obsessive compulsive disorder only. A study in Uganda showed lower (53.3) mean QOL because of the task of caregiving, which was associated with the caregiver's burden. The additional responsibility of the caregivers occupied their time, energy and attention which resulted in higher levels of stress, which was not adequately dealt with [36]. Another study in urban India among caregivers of psychiatric patients showed a low mean QOL score (51.1) which was attributed to caregiver's burden, patient diagnosis, average caregiving hours and caregiving years [37].

The differences in the QOL scores among these countries could be due to the level of adequacy of mental health care besides, the association between different sociodemographic factors affecting the caregiver's QOL [25,38]. The different expectations and provisions of mental health care services in different parts of the world also explain the difference in QOL observed among the different groups of caregivers [26,31].

Caregiver's factors

Caregiver's unmarried marital status, level of education-, and race were significant variables associated with the mean QOL scores. Although women caregivers have been linked to higher burden of care in Africa and India [17,26] and increasing age has been shown to be associated with higher caregiver burden and poorer QOL among caregivers [19,39,40] in this study no statistically significant association between gender, age and QOL scores were seen. Several studies have shown that married caregivers have better QOL compared to their single, widowed, or divorced counterparts. Studies in Iran and Spain have shown that- married caregivers have a higher quality of life [41]. The reason could be because of higher social security, happiness, peace, and effective care [42]. Married caregivers have been shown to have more support, both physically and emotionally which is an important factor in determining caregivers QOL [1,9,13,41].

Studies in Macao [43], England [44] and Korea [45] have shown higher levels of caregiver's education are associated with better QOL. The association is attributed to the greater understanding, acceptance, and awareness of mental health disorders and the willingness to accept the circumstances [43-46]. Caregivers with higher knowledge have been shown to be able to provide better care to patients [43-46]. Higher levels of education is also associated with better understanding of diseases and its various consequences, resulting in caregiver's adaptations to their new role and better coping strategies [17,19,32,45,47-49].

Studies among the Chinese in the United States of America [50], Malaysia [19] and China [31] have shown that Chinese caregivers have higher stigma and burden of care and lower QOL [19,31,50]. The differences in culture and the level of acceptance of mental illnesses in the Chinese community are possible reasons. In Chinese culture, family caregivers undertake the responsibility of taking care of family members

which may result in cause economic burden to the caregivers [13]. Studies in Malaysia [19,20] and Hong Kong showed that caregivers of Chinese patients have lower QOL [26]. Caregivers of Chinese patients have the worst QOL compared to caregivers of Malay patients or Indian patients probably due to the level of acceptance of disease by the Chinese patients. Stigma experienced by the Chinese patients and their relatives could be another reason for the poor caregivers QOL [13,26].

Although studies have shown the association of certain occupations with poor QOL [2,9,17,25]. Socio-economic factors and other related inequalities related to occupations might predispose, precipitate, and perpetuate mental health issues on caregivers [1,2,24-26,38,51]. However, in this study, caregiver's occupation and income have not shown a statistically significant association with caregiver's QOL.

Patient factors

Patient's race was significantly associated with caregiver's QOL. Different races and ethnicities predict different QOL in the caregivers [19,32].

Conclusion

Considering the management of patients with psychiatric illness is moving from institutional care to community care it is imperative that health care providers and policy makers are aware of these factors because decreased QOL of caregivers may impede the quality of care patients may receive from their caregivers.

Limitations

This study is a cross-sectional study design and could be strengthened using a longitudinal study. There are other confounding factors such as caregiving burden, which was not researched in this present study. This factor has been found to explain 3%-12% of the variance seen in the results [26]. Patients in this study are predominantly younger. Therefore it might not reflect the general population of patients. There are also not many detailed comparisons of the reasons affecting the quality of life of caregivers of patients in different nations due to lack of large studies doing the comparison. Therefore there is a lack of space for policy-makers to make policies which are deemed necessary to improve the quality of life of caregivers. The tool used is a translated and back-translated Bahasa Melayu WHOQOL-BREF questionnaire. Therefore it could be that the QOL findings in this paper are over- or under-optimistic of the QOL of caregivers in Malaysia.

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