

# Experience of Family Caregivers of People with Schizophrenia in Hong Kong & Guangzhou

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# Abstract

- Family members charged with the care of those suffering from schizophrenia experience considerable stress due to their multiple responsibilities. The present study quantified the association of the duties of caregivers with mental health symptoms in two Chinese cities having distinct health care systems. 39 caregivers in Hong Kong and 70 caregivers in Guangzhou were recruited through nongovernmental mental health organizations. They were assessed using the Chinese version of the Involvement Evaluation Questionnaire (IEQ) and the General Health Questionnaire (GHQ). While the Guangzhou family caregivers had a significantly higher burden than the Hong Kong sample, there was no significant difference in the psychological health status of family caregivers in the two cities. Result of correlational analyses, however, revealed high associations between burden of care variables and the psychological health of the caregivers.

# Introduction

- In Hong Kong and China, most families take an active role in caregiving of relatives with serious mental illness in their course of recovery (Pearson & Ning, 1997).
- Such caregiving is a task for which the vast majority of people lack adequate training and social supports as the progression of schizophrenia typically creates situations of chronic emotional and physical stress (Huang, Hung, Sun, Lin, & Chen, 2009; Liu, Lambert, & Lambert, 2007; Tsang, Tam, Chan, & Chang, 2003). There is evidence showing that the psychological health and quality of life of caregivers are adversely affected by the caregiving process (Chan, 2001; Pearson & Lam, 2002; Wong, Tsui, Pearson, Chen & Chiu, 2004; Wong, 2000).
- While family members are often invaluable resources, many of them do not anticipate the adverse effects of stress on their physical and mental health and their quality of life.

# Research

- Design
  - convenience sampling method
- Participants
  - In Guangzhou, approximately 100 caregivers who attended a public lecture sponsored by the family resource center on positive psychology approach to caregiving were invited to attend face-to-face interview to complete self-administered questionnaires for this study with 70 completed questionnaires being received.
  - In Hong Kong, with the help of social workers of the NGO for people with mental illness, potential participants were given a written invitation to attend a face-to-face interview for this study. Of the 100 caregivers who received the invitation, 60 consented to participate and 39 completed all questionnaires.

# Demographic characteristics of caregivers by location

Characteristics	Total Sample ( <i>N</i> =109)	Guangzhou Sample ( <i>n</i> =70)	Hong Kong Sample ( <i>n</i> =39)	<i>p</i> <sup>a</sup>
<b>Gender</b>				.055
Men	35(32.1%)	18(25.75)	17(43.6%)	
Women	74(67.9%)	52(74.3%)	22(56.4%)	
<b>Education level</b>				.115
Primary or lower Form 1 to 3	36(32.7%)	23(32.9%)	13(32.5%)	
Form	27(24.5%)	14(20%)	13(32.5%)	
University or above	26(23.7%)	15(21.4%)	11(27.5%)	
	21(19.1%)	18(25.7%)	3(7.5%)	
<b>Marital status</b>				.389
Single	3(2.8%)	1(1.4%)	2(5.1%)	
Married	80(73.4%)	52(74.3%)	28(72.7%)	
Divorced	5(4.6%)	2(2.9%)	3(7.7%)	
Widowed	21(19.3%)	15(21.4%)	6(15.4%)	
<b>Occupation</b>				.000
Other	31(28.4%)	2(2.9%)	29(74.4%)	
Retire	78(71.6%)	68 (97.1%)	10(25.6%)	
<b>Relationship with patient</b>				.005
Parents	89(81.7%)	64(91.4%)	25(64.1%)	
Others	20(18.3%)	6(8.6%)	14(35.9%)	
<b>Age of caregivers</b>	<i>M</i> =64.09 <i>SD</i> =11.69	<i>M</i> =66.53 <i>SD</i> =8.34	<i>M</i> =59.83 <i>SD</i> =15.17	.011

# Research

- Instrument

- Involvement Evaluation Questionnaire (IEQ)

- The IEQ was developed by Schene and Wijngaarden (1992) and Wijngaarden and Schene (1997). It comprises 81 items which is self-administered by the caregivers, it was translated and validated by Tang, Leung and Lam (2008) in Hong Kong, with high test-retest reliability (intraclass correlation coefficient = 0.97; 95% confidence interval = 0.92-0.99), inter-rater reliability (intraclass correlation coefficient = 0.94; 95% confidence interval = 0.86-0.97), and internal consistency (Cronbach's alpha = 0.82).
- The overall core section contains 31 items that assess caregiving consequences, items are scored on a five point Likert scale on frequency, with 0= never, 1= sometimes, 2= regularly, 3= often, 4= always.
- Items in the core section are grouped into four subscales: (a) *Tension* (9 items), (b) *Supervision* (6 items), (c) *Worrying* (6 items), and (d) *Urging* (8 items).

# Research

- Instrument

- General Health Questionnaire

- The instrument was developed by Goldberg (1978) for use in general population surveys; in primary medical care settings; and among general medical outpatients as a first-stage screening instrument for psychiatric illness.
- In this study, the 12-item Chinese version GHQ was adopted (Boey & Chiu, 1998; Chan, 1985). Three GHQ scales were used including (a) total raw score which is the sum ratings for each item, (b) a standard score scale that was derived from a two-point scoring procedure where each item was rated as becoming “worse” (1) or “better” (0), and (c) a psychological risk scale where participants were identified as a “case” (needing psychiatric care) if the sum of their standard scores  $\geq 3$ . If the sum of the standard scores was  $< 3$  the participant was identified as “noncase” (not needing psychiatric care).

# Research

- Data Analysis
  - Correlations were used to assess the relationships between burden and independent variables and psychological health of participants. Between-groups differences (by locations) were evaluated by univariate and multivariate parametric tests.
  - Preliminary Analyses
    - No outliers were identified
    - No demographic variables were found as confounding factors



# Results

- Burden of Caregiving
  - MANCOVA revealed a significant difference on the vectors of means,  $\Lambda = .889$ ,  $F(5, 102) = 2.55$ ,  $p = .032$ . Follow-up ANOVAs showed Guangzhou caregivers had a higher mean, on all IEQ scales,  $p \leq .045$ .
  - There was no difference on the GHQ scores by location.

*Descriptive Statistics of IEQ Scale Scores and GHQ total Scores by Location with Follow-up Between-Group ANOVA Results*

Scales	Total Sample (N=109)		Hong Kong Sample (n=39)		Sample (n=70)		F(1,106)	p
	M	SD	M	SD	M	SD		
IEQ								
Tension	9.49	6.94	6.36	5.44	11.23	7.11	8.43	.004
Supervision	3.83	4.79	2.00	2.96	4.86	5.30	4.12	.045
Worrying	10.95	6.42	8.38	5.99	12.37	6.25	7.90	.006
Urging	10.53	7.28	7.15	6.03	12.41	7.28	6.29	.014
GHQ	13.74	6.85	12.41	5.92	14.49	7.26	1.10	.296

Note.  $\Lambda = .889$ ,  $F(5, 102) = 2.55$ ,  $p = .032$

# Results

- Psychological Health of the Caregivers
  - Forty-four (40.4%) of the total sample were identified as psychological at risk that might need psychological intervention though there was no significant difference between psychological at risk caregivers in Guangzhou and Hong Kong,  $X^2 (1, N = 109) = 0.092, p = 0.76$ .
  - The mean GHQ score in Guangzhou sample ( $M = 14.49, SD = 7.26$ ) was higher than that of Hong Kong ( $M = 12.4, SD = 5.92$ ), however, no significant difference between the Hong Kong and Guangzhou caregivers was found.
  - The mean GHQ score in female caregivers ( $M = 14.09, SD = 6.76$ ) was higher than that of male ( $M = 13.0, SD = 6.91$ ). However, no statistical significant difference between the two sexes were noted.

# Results

- Correlational Findings

- Education level of caregivers was found to have a positive correlation with total IEQ,  $r(107) = .269$ ,  $p = .005$  and in particular with Supervision,  $r(107) = .215$ ,  $p = .025$  and Worrying,  $r(107) = .332$ ,  $p < .001$ .
- Live together period was found to have a positive correlation with total IEQ,  $r(107) = .282$ ,  $p = .003$  and particular with Tension,  $r(107) = .215$ ,  $p = .025$ ; Supervision,  $r(107) = .246$ ,  $p = .01$ ; and the Urging scales,  $r(107) = .300$ ,  $p = .002$
- Age of patient was found negatively correlated with the total IEQ,  $r(107) = -.312$ ,  $p = .001$ , Tension score,  $r(107) = -.214$ ,  $p = .026$ , Worry score,  $r(107) = -.348$ ,  $p < .001$ , and Urging  $r(107) = -.255$ ,  $p = .008$ .

## *Correlation of Demographic Variables with IEQ Scale Scores (N=109)*

	Tension	Supervision	Worrying	Urging	Overall score
Education level of caregiver	.144	.215	.332	.166	.269
<i>p</i>	.135	<b>.025</b>	<b>.000</b>	.084	<b>.005</b>
Live together period	.215	.246	.147	.300	.282
<i>p</i>	<b>.025</b>	<b>.01</b>	.127	<b>.002</b>	<b>.003</b>
Age of patient	-.214	-.145	-.348	-.255	-.312
<i>p</i>	<b>.026</b>	.135	<b>.000</b>	<b>.008</b>	<b>.001</b>

# Results

- Correlational Findings

- The GHQ score of the total sample ( $N= 109$ ) was found to have a significant correlation with the total IEQ and with its subscales.
- The higher the burden, the higher was the GHQ score, i.e. poor health status

*Correlations between Caregiving Burden (IEQ) and Health Status (GHQ) (N=109)*

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	Tension	Supervision	Worrying	Urging	Overall Score
GHQ total score					
<i>r</i>	.57	.33	.54	.21	.52
<i>p</i>	<b>.000</b>	<b>.001</b>	<b>.000</b>	<b>.027</b>	<b>.000</b>

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## *Financial Consequence of Providing Care: % Endorsing Yes*

Financial Consequences	Total Sample (N=109)	Guangzhou Sample (n=70)	Hong Kong Sample (n=39)	$\chi^2(1, N=109)$	<i>p</i>
Professional help for the patient	60(55.0%)	55(78.6%)	5(12.8%)	43.76	<b>&lt; .001</b>
Large expenses incurred by the patient	19(17.4%)	17(24.3%)	2(5.1%)	6.38	<b>0.011</b>
Medicine for the patient	51(46.8%)	46(65.7%)	5(12.8%)	28.15	<b>&lt; .001</b>
Paying debts incurred by the patient.	8(7.27%)	8(11.4%)	0(0%)	4.93	<b>0.028</b>



# Discussion

- As with previous studies (Lau and Pang 2007; Moo et al. 2008), more female caregivers were recruited from the two cities
- Our findings are consistent with the results of the 5-country study in Europe (Wijngaarden et al. 2003) showing that worrying was the most frequently mentioned problem, followed by urging and tension. Supervision was the least mentioned.
- Age of patient also predicted the caregiving burden and caregivers of younger patients experienced greater burden and this is consistent with previous studies (Guitierrez-Maldonado et al. 2005; Harvey et al. 2001), though other local studies did not show similar result (Lau and Pang 2007; Liu et al. 2007; Mo et al. 2008)

# Discussion

- In this study, caregivers with higher education showed higher burden, which is consistent with a local study by Lau and Pang (2007)
- Psychological health indices were correlated with IEQ of the caregivers. Caregivers with higher psychological distress were found to have a heavy caregiving burden. This finding is consistent with previous studies (Monahan et al. 1992; Sisk 2000). In this study it was found GHQ of the total sample was positively correlated with the total IEQ and its subscales which is consistent with previous oversea and local studies (Gutierrez-Maldonado et al 2005; Tang et al. 2008)

# Implication

- Caregivers in Hong Kong and Guangzhou encountered high level of burden and their psychological health was adversely affected. More services like family psychoeducation, support group and individual counseling should be developed aiming at improving psychological health and alleviate their perceived burden.
- In Guangzhou where psychosocial rehabilitation services is developing, more training should be provided to front line workers on basic counseling and supportive psychotherapy for family caregivers .

# Limitation

- A correlational and cross sectional design was adopted which could not investigate causal relationships and changes in burden or psychological health of caregivers over time.
- Convenience sampling method limits the generalization of this study.
- Future research which adopts a longitudinal approach to investigate the effect of coping on burden over time and the effectiveness of family psychoeducation program on alleviating the burden of caregivers is recommended.

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