

## Identification of Factors Influencing Caregiving Experience in Caregivers of Patients with Schizophrenia

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### Introduction

Caregivers of a family member with schizophrenia are undoubtedly affected by their caregiving roles.<sup>1-4</sup> In a previous study, we found that many such caregivers in Singapore experienced clinically important distress.<sup>5</sup> However, factors that influenced caregiving experience of these caregivers are unknown. The purpose of this study was to identify factors that influence caregiving experience in caregivers of a patient with schizophrenia in Singapore.

### Materials and Methods

#### Study Design

A consecutive sample of outpatients with schizophrenia and their caregivers seen in the Institute of Mental Health were recruited for this IRB-approved study. After written consent was obtained, caregivers and patients were surveyed individually during routine counseling by 2 medical social workers (MSWs) who were proficient in both English and Chinese. Caregivers were interviewed using a questionnaire containing the Experience of Caregiving Inventory (ECI)<sup>6</sup> and questions assessing caregiving activities, socio-demographic status and support from various sources in the preceding 3 months. The patients completed a questionnaire containing the Schizophrenia Quality of Life Scale (SQLS),<sup>7</sup> the Short Form 36 Health Survey (SF-36)<sup>8</sup> and questions assessing socio-demographic status. The patients were also assessed for presence of 22 psychiatric symptoms and their utilisation of medications and inpatient services in the preceding 3 months was examined using medical records. All questionnaires were prepared in identical English and Chinese versions for use at interviewees' preference.

Inclusion criteria for patients were: 1) outpatients with a previous diagnosis of schizophrenia; 2) well enough to cooperate with the study; and 3) ability to communicate in English or Chinese. Inclusion criteria for caregivers were: 1) caregiver of a patient with schizophrenia; and 2) ability to communicate in English or Chinese.

#### Instruments

The ECI measures the experience of caring a person with a serious mental illness such as schizophrenia. The ECI consists of 66 items which provide a comprehensive description of caregiving experience in 8 negative dimensions (i.e. difficult behaviours, negative symptoms, stigma, problem with services, effects on the family, need to back up, dependency and loss) and 2 positive dimensions (i.e., rewarding personal experiences and good aspects of relationship with the patient). These dimensions can be consolidated into a negative total score (score range: 0 to 208, higher scores indicating more negative experience) and a positive total score (score range: 0 to 56, higher scores indicating more positive experience).<sup>6</sup> The recall period of the ECI is the past 1 month. Both English and Chinese versions of the ECI have been validated in Singapore.<sup>9</sup>

The SQLS is a 30-item self-report questionnaire which needs 5 to 10 minutes to complete.<sup>7</sup> The instrument measures schizophrenia-specific quality of life/ health status in 3 dimensions (Table I). The

recall period of the instrument is the past 7 days. Both English and Chinese versions of the SQLS have demonstrated acceptable psychometric properties in Singaporeans with schizophrenia.<sup>10</sup>

The SF-36 is a 36-item self-report questionnaire which can be administered in 5 to 10 minutes.<sup>8</sup> The instrument measures self-perceived health status and functioning in 8 dimensions (Table I). The recall period of the SF-36 used in this study was the past 4 weeks. The SF-36 has been intensively validated in many countries including Singapore.<sup>11-13</sup> Both English and Chinese versions of the SF-36 were validated in Singaporeans with schizophrenia.<sup>10</sup>

The psychiatric symptom checklist is designed for trained MSWs to assess patients with schizophrenia for presence or absence of 22 psychiatric symptoms. These symptoms are misery/low spirit, social withdrawal, slowness in movement/activities, forgetfulness, underactivity, over-dependence, unable to make decisions, worrying frequently, unusual fear, compulsive behaviours, delusions/hallucinations, hyperactivity, unpredictability, irritability, rudeness/inconsideration, verbal/physical violence, suicidal expressions/behaviours, offensive/inappropriate sexual behaviours, heavy drinking, lack of self-care, bodily aches/pains and odd behaviours.

#### Statistical Analysis

Multiple linear regression analysis with stepwise methods was used to identify factors that predict caregiving experience measured by the ECI. Thirty-nine variables were studied using 2 multiple linear models, with the ECI negative total scores and the ECI positive total scores being dependent variables respectively. Independent variables covered socio-demographic, health-related and clinical characteristics of the caregivers and/or the patients (Table I). Among these variables, age, duration of caregiving, age of onset of schizophrenia, duration of schizophrenia, number of psychiatric symptoms, expense on psychiatric therapies and patients' self-report health status (measured by the SQLS and SF-36) were treated as continuous variables while the remaining as categorical variables. The criterion significance levels for entry and removal of an independent variable for each step of modelling were chosen to be 0.05 and 0.10, respectively. Analyses were performed with SPSS for Windows (version 11.5).

### Results

#### Subject Characteristics

**Caregivers:** One hundred and fifty-nine eligible caregivers participated in the study. The mean (SD) age of the caregivers was 52.4 (14.1) years, with 58.5% being female. Fifty-two percent of the caregivers were parents of patients and the mean (SD) duration of caregiving was 7.2 (6.9) years. Full socio-demographic characteristics of the caregivers are shown in Table II.

Fifty-six percent, 91.8% and 66.0% of the caregivers reported that they received emotional or practical support from family/friends, spiritual/traditional healers and medical professionals, respectively, in the preceding 3 months. The mean (SD) ECI negative total and

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TABLE I: LIST OF INDEPENDENT VARIABLES

| Variable                                                | Category                        |
|---------------------------------------------------------|---------------------------------|
| <b>Socio-demographic variable</b>                       |                                 |
| Age of caregiver                                        | Continuous                      |
| Age of patient                                          | Continuous                      |
| Gender of caregiver                                     | Male, female                    |
| Gender of patient                                       | Male, female                    |
| Ethnicity of caregiver                                  | Chinese, others                 |
| Marital status of caregiver                             | Married, others                 |
| Marital status of patient                               | Married, others                 |
| Caregiver-patient relationship                          | Parent, others                  |
| Duration of caregiving                                  | Continuous                      |
| Employment status of caregiver                          | Employed, unemployed, homemaker |
| Employment status of patient                            | Employed, unemployed, homemaker |
| Education level of caregiver                            | Primary, secondary, tertiary    |
| Education level of patient                              | Primary, secondary, tertiary    |
| Survey language of caregiver                            | English, Chinese                |
| Survey language of patient                              | English, Chinese                |
| Support from family and friends*                        | Yes, no                         |
| Support from spiritual/traditional healers*             | Yes, no                         |
| Support from medical professionals*                     | Yes, no                         |
| <b>Health-related variable</b>                          |                                 |
| Caregiver's chronic medical conditions                  | Yes, no                         |
| Patient's chronic medical conditions                    | Yes, no                         |
| Psychosocial (SQLS scale)                               | Continuous                      |
| Energy/ motivation (SQLS scale)                         | Continuous                      |
| Symptoms/ side effects (SQLS scale)                     | Continuous                      |
| Physical functioning (SF-36 scale)                      | Continuous                      |
| Role limitation due to physical problems (SF-36 scale)  | Continuous                      |
| Bodily pain (SF-36 scale)                               | Continuous                      |
| General health (SF-36 scale)                            | Continuous                      |
| Vitality (SF-36 scale)                                  | Continuous                      |
| Social functioning (SF-36 scale)                        | Continuous                      |
| Role limitation due to emotional problems (SF-36 scale) | Continuous                      |
| Mental health (SF-36 scale)                             | Continuous                      |
| <b>Patient's clinical variable</b>                      |                                 |
| Age of onset of schizophrenia                           | Continuous                      |
| Duration of schizophrenia                               | Continuous                      |
| Number of psychiatric symptoms                          | Continuous                      |
| Recent admission in a psychiatric ward*                 | Yes, no                         |
| Usage of typical antipsychotics*                        | Yes, no                         |
| Usage of atypical antipsychotics*                       | Yes, no                         |
| Usage of depot antipsychotics *                         | Yes, no                         |
| Expense on psychiatric therapies*                       | Continuous                      |

\* In the preceding 3 months.

positive total scores were 77.6 (31.8) and 29.2 (9.8) points, respectively.

**Patients:** The mean (SD) age of the patients (n = 159) was 37.2 (10.8) years, with 50.3% being female and 58.5% surveyed on the same day when their caregivers were surveyed. The mean (SD) age of onset of schizophrenia was 29.2 (10.9) years. The majority of the patients were unmarried (69.2%) and unemployed (64.2%). Full socio-demographic characteristics of the patients are shown in Table II.

In the preceding 3 months, 31.4% of the patients had been admitted to a psychiatric ward; 86.8%, 28.3% and 57.2% was on typical, atypical and depot antipsychotics, respectively. The median (interquartile) expense on these therapies during the period was \$166.40 (\$80.90, \$360.50). At the time of interview, the mean (SD) number of psychiatric symptoms was 4.9 (3.2). Patients' SF-36 scores were substantially worse than Singaporean population norms ( $p < 0.05$  for all, one-sample t-tests, Table III).

#### Factors Influencing Negative Experience of Caregiving

The regression analysis for ECI negative total scores yielded 6 variables, indicating that these factors influenced negative caregiving

TABLE II: SOCIO-DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS AND PATIENTS

|                                        | %, unless otherwise stated |                 |
|----------------------------------------|----------------------------|-----------------|
|                                        | Caregiver (n=159)          | Patient (n=159) |
| Mean (SD) age, years                   | 52.4 (14.1)                | 37.2 (10.8)     |
| Female gender                          | 58.5                       | 50.3            |
| Ethnicity                              |                            |                 |
| Chinese                                | 83.6                       | 84.3            |
| Malay                                  | 8.2                        | 10.1            |
| Indian/others                          | 8.2                        | 5.6             |
| Education                              |                            |                 |
| Primary or lower                       | 46.5                       | 30.9            |
| Secondary                              | 45.3                       | 56.5            |
| Tertiary                               | 8.2                        | 12.6            |
| Marital status                         |                            |                 |
| Single                                 | 18.2                       | 69.2            |
| Married                                | 59.1                       | 23.9            |
| Divorced/separated/widowed             | 22.7                       | 6.9             |
| Employment status                      |                            |                 |
| Employed                               | 47.8                       | 10.0            |
| Unemployed                             | 11.3                       | 64.2            |
| Homemaker                              | 40.9                       | 25.8            |
| Presence of chronic medical conditions | 46.5                       | 15.1            |
| Survey language (English)              | 60.4                       | 70.4            |
| Relationship                           |                            |                 |
| Parent                                 | 51.6                       |                 |
| Spouse                                 | 17.6                       |                 |
| Sibling                                | 17.6                       |                 |
| Child/others                           | 13.2                       |                 |

TABLE III: PATIENTS' SELF-REPORT HEALTH STATUS

| Health status scale                        | Mean (SD)   | Singaporean population norms* |
|--------------------------------------------|-------------|-------------------------------|
| <b>SQLS</b>                                |             |                               |
| Psychosocial                               | 37.8 (21.1) |                               |
| Energy/motivation                          | 46.1 (16.3) |                               |
| Symptoms/side effects                      | 27.5 (18.7) |                               |
| <b>SF-36</b>                               |             |                               |
| Physical functioning                       | 74.1 (19.4) | 83.9                          |
| Role limitations due to physical problems  | 45.9 (40.8) | 84.9                          |
| Bodily pain                                | 76.8 (23.4) | 81.1 <sup>a</sup>             |
| General health                             | 56.5 (21.5) | 68.5                          |
| Vitality                                   | 54.8 (19.6) | 63.4                          |
| Social functioning                         | 65.6 (27.4) | 76.3                          |
| Role limitations due to emotional problems | 47.7 (42.9) | 82.1                          |
| Mental health                              | 58.9 (19.1) | 72.5                          |

Scores for all scales range from 0 to 100 (higher SQLS scores indicate worse quality of life/ health status while higher SF-36 scores indicate better health status and functioning); \*adjusted for age, gender, ethnicity and survey language (English/ Chinese)<sup>13</sup>;  $p < 0.001$  for all unless otherwise specified; <sup>a</sup> $p = 0.023$  (one-sample t-tests);

experience. These factors and their relationships with negative caregiving experience were: caregivers' perceived support from professionals, lower expense on psychiatric therapies and patients' being married, experiencing less psychiatric symptoms, worse mental status or less role limitations due to physical problems were associated with less negative caregiving experience. Effect sizes of these factors are shown in Table IV.

#### Factors Influencing Positive Experience of Caregiving

The regression analysis for ECI positive total scores yielded 4 variables, indicating that these factors influenced positive caregiving experience. These factors and their relationships with positive caregiving experience were: caregivers' perceived support from family/friends, caregivers' speaking English, patients' recent admission to a psychiatric ward or experiencing more role limitations due to physical problems were associated with more positive caregiving experience. Effect sizes of these factors are shown in Table V.

TABLE IV: EFFECT SIZES OF FACTORS SELECTED BY THE LINEAR MODEL FOR ECI NEGATIVE TOTAL SCORES

|                                           | Effect size (unstandardised) | P value |
|-------------------------------------------|------------------------------|---------|
| Total expenses on therapies*              | 0.02                         | < 0.001 |
| Number of psychiatric symptoms            | 2.79                         | 0.001   |
| Support from medical professionals* (yes) | -12.28                       | 0.012   |
| SF-36 mental health scores                | 0.38                         | 0.003   |
| SF-36 role-physical scores                | -0.14                        | 0.019   |
| Patients' marital status (married)        | -11.35                       | 0.042   |

Adjusted R<sup>2</sup>: 24.5%; \* in the preceding 3 months.

TABLE V: EFFECT SIZES OF FACTORS SELECTED BY THE LINEAR MODEL FOR ECI POSITIVE TOTAL SCORES

|                                                  | Effect size (unstandardised) | P value |
|--------------------------------------------------|------------------------------|---------|
| Support from family and friends (yes)*           | 3.83                         | 0.015   |
| Patients' admission in a psychiatric ward (yes)* | 4.02                         | 0.017   |
| SF-36 role-physical scores                       | -0.05                        | 0.017   |
| Caregivers' survey language (English)            | 3.56                         | 0.028   |

Adjusted R<sup>2</sup>: 9.7%; \* in the preceding 3 months.

## Discussion

In this cross-sectional study, we identified a variety of factors that may influence caregiving experience in caregivers of a patient with schizophrenia. To the best of our knowledge, this was the first study with the aim to understand the experience of such caregivers in Singapore.

Some findings in our study are consistent with those in the literature. We found caregivers' self-perceived support was associated with better caregiving experience. Previous studies have shown that self-perceived support from family<sup>14</sup> or professionals<sup>15</sup> was associated with less burden for caregivers of persons with mental disorders. In addition, the observed relationship between patients' psychiatric symptoms and negative caregiving experience in our study has been a replicated finding in the literature.<sup>16,17</sup>

On the other hand, our finding that patients' worse role functioning was associated with more positive caregiving experience is contrasted with a previous finding that poorer social functioning of patients with severe mental disorders was associated with less positive caregiving experience.<sup>18</sup>

In this study, we also found factors of caregiving experience that, to the best of our knowledge, have not been reported in the literature. Some of these new findings may reflect cultural differences in perception of caregiving experience between the West and Singapore. For example, caregivers of married patients perceived less negative caregiving experience in Singapore. Another example is that higher expense on psychiatric therapy was associated with more negative caregiving experience, which may reflect the fact that many of these Singaporean families were from lower socio-economic class.

Limitations of this study include recruiting subjects from only 1 medical centre, which may limit the generalisation of our findings. Another limitation is that only English and Chinese-speaking caregivers and patients were included in the study, as Malay and Tamil versions of the ECI were not available.

Findings in our study, though preliminary, do justify further

studies into those factors that may influence caregiving experience in Singapore. Once these factors and their relationships with caregiving experience are clarified, health professionals may better help these caregivers who play an important role in management of patients with schizophrenia.

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