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## Psychological trauma among family caregivers of individuals with schizophrenia in relation to their subjective care burden, distress and stress response

Tetsuya Miyagi<sup>1)</sup>, Takehiko Toyosato<sup>2)</sup>, Misuzu Takahara<sup>2)</sup> and Takao Yokota<sup>2)</sup>

<sup>1)</sup>Graduate School of Health Sciences, University of the Ryukyus

<sup>2)</sup>School of Health Sciences, University of the Ryukyus

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### ABSTRACT

The present study aimed to clarify which symptoms/behaviors in individuals with acute schizophrenia mainly cause psychological trauma in their family caregivers and how psychological trauma consequently induces subjective care burden, distress and stress response in family members. Psychological trauma as symptoms for post-traumatic stress disorder (PTSD) was assessed by the Impact of Event Scale-Revised (IES-R) while the Family Burden and Distress Scale (FBDS) and Stress Response Scale-18 (SRS-18) were used to evaluate secondary emotion reaction. The recovery of the questionnaires was 30.9% (117 out of 379). Among them, 78 cases, who completely replied to all the questions, were selected as the subjects, who were divided into two groups by the cut off value (24/25) for IES-R, i.e., low-risk (n = 45) and high-risk (n = 33) groups for psychological trauma. Only agitation in patients significantly contributed to the increased proportion of the high-risk groups in family caregivers. Greater Burden (odds ratio = 5.12), Confusion (5.72) and stress response with depression/anxiety (2.94) were observed in the high-risk group. These suggest that patient's agitation has strong impact on traumatic stress in family caregivers, who may eventually show increased care burden and depressive/anxious response as the secondary process. *Ryukyu Med. J., 33 (1~3) 45~52, 2014*

Key words: family caregivers of schizophrenia patients, psychological trauma, family burden and distress, stress response

### INTRODUCTION

Family members play a significant role in supporting the independence of mentally disabled individuals, and factors affecting family members also strongly affect the probability of relapses and social functioning of the impaired individual. Family caregivers also suffer from a significant burden from providing care and treatment to the impaired individual, due to factors such as difficulty in understanding their illness and interaction and the associated financial burden<sup>1)</sup>. Among mental disorders, schizophrenia tends to be highly chronic, and social prejudice and stigma interfere with positive understanding and social support from others, creating an even larger psychological and

social burden on family members<sup>2)</sup>. According to a survey on family support conducted by the Japanese Ministry of Health, Labour and Welfare in fiscal 2009<sup>3)</sup>, 79.5% of mentally disabled individuals live with their family. When the individual's condition worsens, the most common difficulties and distress felt by family caregivers are fear of the sufferer (felt by 64.8% of family members), followed by psychological effects on the family members (58.7%) and increasing worries about physical danger (30.9%). In addition, acute symptoms from hallucinations and delusions occurring when psychiatric symptoms become aggravated may trigger post-traumatic stress disorder (PTSD) and affect acceptance by family members<sup>4)</sup>.

PTSD is a diagnostic concept that was first classified in 1980 under the diagnostic criteria of

the third edition Diagnostic and Statistical Manual of Mental Disorders (DSM-III) by the American Psychiatric Association. It is currently widely accepted as a syndrome occurring after any emotional trauma, regardless of the type of cause<sup>5</sup>. The concept of PTSD became well known in Japan in the aftermath of the Great Hanshin-Awaji Earthquake, during which 12.9% of men and 9.0% of women were reported to suffer from the disorder<sup>6</sup>. Past studies on the effects of PTSD on quality of life (QOL) have shown significantly lower QOL scores among those with PTSD following a traffic accident compared to controls<sup>7</sup> and have shown PTSD core symptoms to lower QOL and impair daily functioning<sup>8</sup>. Moreover, PTSD may have significant effects on daily life as a whole, including physical and mental role functioning and social functioning<sup>9</sup>.

A previous study on schizophrenia and psychological trauma has suggested that 57.9% of individuals with a schizophrenic family member who required long-term hospitalization may suffer from psychological trauma<sup>4</sup>. A survey by Loughland et al.<sup>10</sup> showed that psychological trauma may be present in over half of family members of schizophrenic patients. As individuals suspected of having psychological trauma have been reported to exhibit a stronger psychological stress response<sup>6</sup>, psychological trauma may have strong effects on the physical and mental health of family caregivers. In particular, stress vulnerability and hypersensitivity accompanying psychological trauma in family caregivers of individuals with schizophrenia may lead to various psychological burdens, such as a feeling of difficulty or burden in caregiving resulting from the disease of the patients, uncertainty about the future, or depression and feelings of isolation. Research on psychological trauma in family members of individuals with schizophrenia has only just begun in Japan. A preliminary survey we conducted revealed psychological trauma in nearly 40% of family members, and indicated that a psychological trauma led to reductions in the ability to solve problems caused by schizophrenia, a large subjective sense of care burden, and the ability to cope with stress that increases the occurrence of stress response<sup>11</sup>. However, the sample size of that investigation was small, with only 69 subjects, and was therefore limited in its power to evaluate concrete psychiatric symptoms related to acute

symptoms of schizophrenia when measuring psychological trauma. We therefore set out to determine how psychiatric symptoms in individuals with schizophrenia in an acute state influence the psychological trauma in family caregivers of the individual and to examine the effects on subjective difficulty and burden in providing care as well as psychological stress response.

## SUBJECTS AND METHODS

Questionnaires were distributed by mail to 379 family members of inpatients and outpatients with schizophrenia at the psychiatric department of hospital A in Okinawa in October and November 2012. 117 family members responded. And agreed to cooperate with investigation with IES-R. 78 out of 117 who replied to all the questions were chosen as the target.

To describe basic attributes, the questionnaires included questions on gender, age, relationship with the patient, educational background, financial situation, health status, and present illnesses. Psychological trauma was measured with the Japanese version of the Impact of Event Scale - Revised (IES-R) created by Asukai et al.<sup>12</sup> that has been confirmed to have high reliability and validity<sup>13</sup>. The IES-R is a scale in which responses are given concerning a single traumatic event such as an earthquake, incident or accident that caused major stress. In the present study, participants were given a written explanation stating that they would be asked about the time when the schizophrenic family member's symptoms were the strongest. Based on the literature<sup>14-16</sup>, participants were asked to respond regarding a specific event shown to be a main acute positive symptom expressed during schizophrenia from among violence, verbal aggression, agitation, bizarre behavior and severe physical violence. For IES-R evaluation, each item was rated on a five-point scale from 0 = not at all to 4 = extremely, with higher scores indicating a higher psychological trauma. The Cronbach  $\alpha$  coefficient for this scale in the present study was 0.96, and high internal consistency was observed for the subscales of intrusion ( $\alpha = 0.92$ ), avoidance ( $\alpha = 0.90$ ) and hyperarousal ( $\alpha = 0.90$ ).

The Family Burden and Distress Scale (FBDS)

developed by Yamaguchi *et al.*<sup>17)</sup> was used as a scale to measure subjective difficulty and burden of family members accompanying onset of the patient's illness. A characteristic of the FBDS is that it measures not only the psychological burden of patient care but also the shock associated with the onset of the patient's illness, various difficulties resulting from a lack of understanding of the illness, uncertainty about the future, depression, isolation, distress about the relationship with the patient, and other psychological phenomena and difficulties faced by family members of the patient. This scale is comprised of 24 items in three subscales: subjective burden and depression resulting from the patient's illness ("Burden"), confusion resulting from a lack of knowledge of the illness and anxiety about the future ("Confusion") and difficulties in the relationship with the patient ("Relationship"). The FBDS is rated on a four-point Likert scale from 1 = strongly disagree to 4 = strongly agree, with higher scores indicating higher subjective difficulty and sense of burden. The Cronbach  $\alpha$  coefficient for this scale in the present study was 0.90, and internal consistency was generally observed for the subscales of Burden ( $\alpha = 0.90$ ), Confusion ( $\alpha = 0.91$ ) and Relationship ( $\alpha = 0.69$ ).

The Stress Response Scale-18 (SRS-18) was validated for internal consistency and discriminant validity by Suzuki *et al.*<sup>18)</sup> The SRS-18 is a questionnaire that measures various aspects of psychological stress response in stressful scenarios experienced in daily life and is comprised of 18 items in three subscales: depression-anxiety, irritability-anger, and helplessness. Each item is rated on a four-point scale from 3 = strongly agree to 0 = strongly disagree, and the total score is the sum of the points from all items. Higher scores indicate higher psychological stress responses. The Cronbach  $\alpha$  coefficient for the SRS-18 in the present study was 0.93, and high internal consistency was observed for the subscales of depression-anxiety ( $\alpha = 0.87$ ), irritability-anger ( $\alpha = 0.89$ ), and helplessness ( $\alpha = 0.85$ ).

In analysis, we determined the appropriate cutoff for total IES-R score to be 24/25 points<sup>12)</sup>, and therefore divided participants into a high-risk group of 25 points or more and low-risk group of less than 25 points in the IES-R. For the FBDS and SRS-18 scales, participants were divided into high and low groups at the median of the total scores

and subscale scores. Logistic regression analysis was performed with FBDS and SRS-18 as dependent variables and IES-R as the independent variable. Univariate analysis was first performed on the relationships between FBDS, SRS-18 and personal attributes; variables found to be significant were added to the logistic regression as control variables. SPSS17.0J statistical software was used for analysis with a 5% level of significance.

As an ethical consideration, participants were informed orally or in writing the purpose of the study, that responses would be anonymous and were voluntary, that they could withdraw at any time and would suffer absolutely no consequences should they withdraw, and that the survey data would be destroyed after statistical processing. The submission of a completed questionnaire was deemed as providing consent. This study was approved by the ethics committee in clinical research at the University of the Ryukyus and the hospital A ethics committee.

## RESULTS

In the high-risk group defined by the IES-R score, the ratio of respondents was 42.3% (33 people), which was higher than 40%. Comparisons of basic attributes and IES-R (Table 1) showed a higher proportion of men in the low-risk group (51.1%) and of women in the high-risk group (54.5%). The mean age was over 60 for both groups (low-risk group:  $63.3 \pm 12.9$  years, high-risk group:  $60.2 \pm 12.9$  year).

Poor financial status made up the majority of both groups (low-risk group: 68.9%, high-risk group: 72.7%). More respondents lived together with the patient in the low-risk group (64.3%) and lived apart in the high-risk group (58.1%). However, none of these differences were statistically significant, suggesting that background variables of the subjects have little effect on whether they were high-or low-risk.

The psychiatric symptoms related to a psychological trauma are shown in Table 2. The highest rating of presence of a symptom was for bizarre behavior (65.4%), followed by agitation (38.5%), verbal aggression (34.6%), and violence (20.5%). Comparisons of psychiatric symptoms between groups showed a significant difference only for agitation, with a significantly higher ratio in the

Table 1 The effects of backgrounds of family caregivers on the risk of psychological trauma assessed by the Impact of Event of Scale-Revised

		IES-R		n(%)
		Low	High	P-value
Sex	Male	23(51.1)	15(45.5)	0.653
	Female	22(48.9)	18(54.5)	
Age	Mean $\pm$ SD	63.3 $\pm$ 12.9	60.2 $\pm$ 12.9	0.497
Subjective economic status	Good	14(31.1)	9(27.3)	0.804
	Poor	31(68.9)	24(72.7)	
Living with patient	Yes	27(64.3)	13(41.9)	0.095
	No	15(35.7)	18(58.1)	

Mann-Whitney U test or Chi-square test

IES-R: Impact of Event Scale-Revised

Low: low-risk group in the IES-R. High: high-risk group in the IES-R

Table 2 The effects of patients symptoms/behaviors on the risk of psychological trauma assessed by the Impact of Event of Scale-Revised

		IES-R			n(%)
		Total (n=78)	Low (n=45)	High (n=33)	P-value
Bizarre behavior	Yes	51(65.4)	27(60.0)	24(72.7)	0.246
	No	27(34.6)	18(40.0)	9(27.3)	
Agitation	Yes	30(38.5)	12(26.7)	18(54.5)	<b>0.013</b>
	No	48(61.5)	33(73.3)	15(45.5)	
Verbal aggression	Yes	27(34.6)	12(26.7)	15(45.5)	0.087
	No	51(65.4)	33(73.3)	18(54.5)	
Violent behavior	Yes	16(20.5)	6(13.3)	10(30.3)	0.068
	No	62(79.5)	39(86.7)	23(69.7)	
Severe physical violence	Yes	12(15.4)	4(8.9)	8(24.2)	0.065
	No	66(84.6)	41(91.1)	25(75.8)	

Chi-square test

IES-R: Impact of Event Scale-Revised

Low: low-risk group in the IES-R. High: high-risk group in the IES-R

high-risk group ( $p = 0.013$ ).

The results of multiple logistic regression on FBDS and IES-R are shown in Table 3. A significant relationship was seen with total FBDS score (odds ratio (OR): 4.6, 95% CI: 1.63-13.15,  $p = 0.004$ ) and the subscales of Burden (OR: 5.1, 95% CI: 1.87-14.02,  $p = 0.001$ ) and Confusion (OR: 5.7, 95% CI: 1.89-17.32,  $p = 0.002$ ), with a significantly higher score for each in the high-risk group.

The results of multiple logistic regression on psychological stress response and IES-R are shown in Table 4. A significant relationship was observed

with the depression-anxiety subscale (OR: 2.9, 95% CI: 1.11-7.77,  $p = 0.030$ ), with significantly greater depression-anxiety scores in the high-risk group.

## DISCUSSION

Comparison of psychological trauma and psychiatric symptoms between groups showed a significantly higher prevalence of agitation in the high-risk group than in the low-risk group. The agitation shown in acute symptoms of schizophrenia

Table 3 Correlation between Impact of Event of Scale-Revised and Family Burden and Distress Scale by logistic regression analysis

		FBDS			
		Burden <sup>#1</sup>	Confusion <sup>a#2</sup>	Relationship <sup>b#3</sup>	Total Score
		OR(95%CI)	AOR(95%CI)	AOR(95%CI)	OR(95%CI)
IES-R	Low	1.00	1.00	1.00	1.00
	High	<b>5.12(1.87–14.02)***</b>	<b>5.72(1.89–17.32)**</b>	1.32(0.47–3.70)	<b>4.63(1.63–13.15)**</b>

\*\*p < 0.01, \*\*\*p = 0.001

IES-R: Impact of Event Scale-Revised

FBDS: Family Burden and Distress Scale

Independent variables: IES-R

Dependent variable: FBDS total score and subscales

Low: low-risk group in the IES-R. High: high-risk group in the IES-R

OR: Odds Ratio, AOR: Adjusted Odds Ratio, 95% CI: 95% confidence interval

a: Adjusted for education, b: Adjusted for living with patient

#1 Subjective burden and depression resulting from the patients illness

#2 Confusion resulting from lack of knowledge of the illness and anxiety

#3 Difficulties in the relationship with the patient

Table 4 Correlation between Impact of Event of Scale-Revised and Stress Response Scale-18 by logistic regression analysis

		SRS-18			
		Depression-anxiety	Irritability-anger <sup>a</sup>	Helplessness <sup>a</sup>	Total Score <sup>a</sup>
		OR(95%CI)	AOR(95%CI)	AOR(95%CI)	AOR(95%CI)
IES-R	Low	1.00	1.00	1.00	1.00
	High	<b>2.94(1.11–7.77)*</b>	4.39(0.72–26.77)	4.40(0.86–22.36)	1.93(0.32–11.45)

\*p<0.05

IES-R: Impact of Event Scale-Revised

SRS-18: Stress Response Scale-18

Independent variables: IES-R

Dependent variable: SRS-18 total score and subscales

Low: low-risk group in the IES-R. High: high-risk group in the IES-R

OR: Odds Ratio, AOR: Adjusted Odds Ratio, 95% CI: 95% confidence interval

a: Adjusted for age

is a state of speech and actions based on pathological symptoms such as auditory hallucinations and persecutory delusions<sup>19</sup>). Distinctive behavioral problems shown by patients in an acute state such as agitation may become a large psychological burden to the patient's family members and may greatly affect their attitude towards the patient. Acute symptoms of schizophrenia such as agitation are risk factors for violent actions<sup>20</sup>). A previous study showed a significantly higher prevalence of verbal aggression among those at high risk of having psychological trauma<sup>21</sup>). The present study also shows that acute symptoms may be a major risk factor of psychological trauma.

Analysis of FBDS scores showed that the psychological trauma was significantly related to

Burden in the high-risk group, suggesting that the psychological trauma contributes to the subjective sense of care burden and to depression in family members. Difficulties that family members may experience when caring for patients include confusion about the patient's behavior, issues with compulsory treatment and protection, inability to control the patient, and violence by the patient<sup>22</sup>). Moreover, the literature shows that the many opportunities family caregivers of individuals with schizophrenia have for direct contact with those individuals may result in moderate to severe physical and/or psychological difficulties in family caregivers<sup>21</sup>). Hanzawa et al.<sup>21</sup>) examined the relationship between psychological trauma in family caregivers of individuals with schizophrenia

and sense of care burden and found that family caregivers frequently experienced verbal aggression affecting their sense of distress and care burden, and that psychological trauma is strongly related to sense of care burden in family caregivers who have been victims of violent acts from the individual with schizophrenia. Miyagi et al.<sup>11)</sup> found that psychological trauma in family caregivers is affected by poor abilities to cope with stress and to resolve problems caused by the patient's illness, and suggest that such factors may increase subjective sense of care burden. The results of the present study also support those findings. We also found a significant relationship with the Confusion subscale, suggesting that family caregivers with psychological trauma have a high risk of confusion and uncertainty about the future due to a lack of knowledge about the illness that may contribute to a sense of care burden. A previous study on the relationship between satisfaction with the level of information and psychological burden in family caregivers of individuals with schizophrenia found that psychological burden increases with decreasing satisfaction with the level of information about schizophrenia, such as the cause and treatment<sup>23)</sup>. Family caregivers often do not receive adequate information and support from mental health professionals and continue providing care and nursing care while feeling a lack of knowledge and/or competence<sup>24)</sup>. In addition, it has been suggested that uncertainty about the future lies at the core of care difficulties in family caregivers of individuals with schizophrenia<sup>25)</sup>. Indeed, one study has shown that acquiring accurate knowledge about the disease and how to interact with the patient makes it easier for family caregivers to construct a mental picture of the future<sup>26)</sup>. The results of the present study suggest that an important task for supporting family caregivers of individuals with schizophrenia is to help relieve their confusion and uncertainty about the future. Doing so may be beneficial as a measure for improving mental health including psychological trauma in family caregivers.

Our examination of the relationship between psychological trauma and psychological stress response showed a significant association with the depression-anxiety subscale, suggesting that vulnerability to stress may be associated with the psychological trauma in family caregivers. Psychological stress responses refer to emotional,

cognitive and behavioral changes arising from various stressors experienced in daily life<sup>18)</sup>. Owashi et al.<sup>27)</sup> examined the relationship between psychological trauma and vulnerability to stressors; they found that those with chronic psychological trauma have a higher likelihood of having a new traumatic experience. As most cases of schizophrenia are chronic, a psychological trauma in family caregivers may be expected to become prolonged and continue over the long term. This may result in a weak stress tolerance and increased susceptibility to having a stress response.

In assisting family caregivers, an important challenge will be to develop concrete support measures to suit each caregiver's unique situation through the patient's medical institution or home visits. Such measures can include, for example, education for the caregiver on the psychology related to acute symptoms of schizophrenia that trigger of psychological trauma, proposals for coping methods and long-term treatment plans for both the patient and the family caregivers, and provision of opportunities such as family meetings for communication between the patient and family members as well as an environment for family members to have temporary reprieve.

## STUDY LIMITATIONS

Questionnaires were distributed by mail to 379 family members of inpatients and outpatients with schizophrenia at the psychiatric department of hospital A in Okinawa. However, since the number of our samples is 78, which is relatively small in the size, there is a possibility that these results might be considered as "type II error", which could lead to the conclusion where there is no psychological trauma. Thus, to overcome this problem, it is necessary to increase the number of samples for our further studies. The diagnosis of the PTSD can be measured in two ways: a structured interview and self-administered questionnaires. Some of the well-known structured interviews are Structured Clinical Interview for DSM-IV (SCID), MINI International Neuropsychiatric Interview (M.I.N.I.), and Clinician-Administered PTSD Scale (CAPS). On the other hand, some of the widely used measurement for the self-administered questionnaires are Posttraumatic Symptoms Scale

(PTSS-10), Impact of Event Scale (IES), and IES-R, the measurement we used for this study. For diagnosing PTSD, it is necessary to perform structured interviews such as SCID, M.I.N.I, or CAPS as they provide more accurate data; however, taking into burden of participants, we adopted IES-R which is relatively easy to self-administered, and it is being used for subjects with various groups who were exposed in such traumatic experiences. Despite these limitations, we were able to confirm the possibility that agitation based on the hallucinations and delusions characteristic of schizophrenia can trigger emotional trauma such as psychological trauma in family or nonrelative caregivers, and that agitation may increase care burden and weaken stress tolerance. We also showed that the IES-R scale shows great potential for clinical application as an easy and very convenient index with a low burden to measure psychological trauma in family caregivers of individuals with schizophrenia.

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