Community-based Intervenational Programmes for Family Caregivers of Persons with Traumatic Brain Injury

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Abstract: The purpose of this study is to verify the effects of interventional programmes to reduce the psychological distress of family caregivers of persons with traumatic brain injury. An interventional programme was conducted over five sessions which were held for four hours and took place once a week, involving a total of 16 persons. The interventional programme mainly consisted of providing basic knowledge of traumatic brain injury, ways of treating cognitive dysfunction and training of communication skills applying assertiveness training. Evaluation criteria were GHQ-30, SDS, STAI, and RAS as assessment measures and were analysed before and after the intervention and at three month and six month follow-ups after the interventional programme. A considerable reduction of the mean score was statistically recognised compared with SDS at pre-intervention and after the six month follow-up, and STAI at pre-intervention and post-intervention in the analysis of variance of pre- and post-intervention and follow-ups.

Key words: traumatic brain injury, family interventions, communication skills training, assertiveness training for family

Introduction

Cognitive dysfunction caused by traumatic brain injury affects the ability to respond to and process information, memory, attention, and stimulus of patients (Lezak, 2004). Among patients with traumatic brain injury, some exhibit neurobehavioral changes such as aggressiveness and self-centeredness and have difficulty performing daily living and social activities. Furthermore, aggressive language and behaviour are said to worsen, whereas other disability indexes improve over time (Brooks, Campsie, Symington, Beattie & McKinlay, 1987). Family members are confused by such changes in patients with traumatic brain injury and feel the burden of their care. Hall et al. (1994) indicate that the behavioural factors which cause family caregivers of persons with traumatic brain injury to experience the burden are those such as severe emotional outbursts, self-centeredness, slowness, forgetfulness and aggressiveness. In addition, Kreutzer, Gervasio, and Camplair (1994a) report behaviour problems and emotional and personality disturbances as behavioural factors (Kreutzer, Marwitz & Kepler, 1992), while Brooks and McKinlay (1983) report personality change as a factor.

Moreover, evidence has been accumulated from recent decades of research that most family caregivers have psychological distress such as depression and anxiety caused by the neurobehavioral change of patients with traumatic brain injury (Perlesz, Kinsella & Crowe, 1999). Despite this evidence, both domestic and international, few intervention studies have been conducted to reduce the psychological distress of family caregivers of persons with traumatic brain injury (Boschen, Gargaro, Gan, Gerber & Brandys, 2007). Previous international studies have been trying to reduce the psychological distress of family caregivers through interventions such as information instruction on cognitive dysfunction (Sanguinetti & Catanzaro, 1987), behaviour management programmes (Carnevale, Anselmi, Busichio & Millis, 2002), stress management programmes (Singer et al., 1994) and problem-solving training (Rivera, Elliott, Berry & Grant, 2008). However, methodology problems have been reported, such as most of the preceding studies using as-
of candidates was limited to 20 persons in total (10 persons at each meeting site) because the interventional programme consisted of communication skills training with role-playing. After a three-month period from the start of recruitment, we received 16 applicants and all of the 16 applicants fulfilled the preconditions. We randomly divided the 16 applicants in half, allocating them to Kobe and Osaka sites, and conducted the interventional programme. This study was approved by the ethics committee of Kobe University Graduate School of Health Science (Date of approval, December 8th, 2009).

**Assessment measures**

The following assessment measures were used for evaluation of the degree of psychological distress and assertiveness of family caregivers.

1. The General Health Questionnaire-30 (GHQ-30) (Goldberg, 1978)
   
   This is an assessment measure consisting of 30 items in a self-administered questionnaire. It is a screening device for clarifying the mental health status of the respondent. Higher scores indicate lower mental health. The GHQ-30 Japanese version was used (Nakagawa & Obo, 1985).

2. Self-rating Depression Scale (SDS) (Zung, 1965)
   
   This is an assessment measure consisting of 20 items in a self-administered questionnaire to examine depression in the respondent. Higher total scores indicate greater depression. SDS Japanese version was used (Fukuda & Kobayashi, 1983).

3. Stated-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch & Lushene, 1970)
   
   This is an assessment measure consisting of 40 items in a self-administered questionnaire. 20 items pertain to Stated Anxiety, which examines how the patient feels at the moment and 20 items pertain to Trait Anxiety, which inquires about the general feeling of the subject. Higher total scores indicate greater anxiety. STAI Japanese version was used (Mizuguchi, Shimonaka & Nakasato, 1991).

4. Rathus Assertiveness Schedule (RAS) (Rathus, 1973)
   
   RAS is an assessment measure consisting of 30 items assessing assertiveness. In this study, we followed the RAS scoring method. Each item is scored from –3 to +3 excluding 0. +3 means very characteristic of me, or extremely descriptive and –3 means very uncharacteristic of me, or extremely non-descriptive. The scale ranges from –90 (least assertive) to +90 (most assertive). The higher the score the more assertive the respondent. RAS is multipurpose and has been widely utilized including assertiveness training in adolescent character development enhancement programs for high school students (Kessler, Ibrahim & Kahn, 1986), the effect of assertiveness train-
ing for sociophobic patients (Cottraux, Mollard & Defayolle, 1982) and a study of anxiety and assertiveness in the relatives of alcoholics (Schuckit, 1982). It is possible to use RAS in the field of Health and Welfare. The reliability and validity of RAS has been verified by several researchers (Linehan & Walker, 1983; McCartan & Hargie, 1990). RAS Japanese version was used (Shimizu et al. 2003).

**Procedure**

The participants were explained the purpose and method of the study, and consent to participate in this study was granted. The descriptive information regarding the participants and the patients with traumatic brain injury was collected and confirmed, and we received answers to the assessment measures of GHQ-30, SDS, STAI, and RAS which was set as the pre-intervention variable. We conducted the interventional programme a total of five times, once weekly, for four hours each time. After the fifth session, we once again received answers to the assessment measures and set this as the post-intervention variable. At three months and six months after finishing the interventional programme, we mailed assessment measures to the participants as follow-up variables. After finishing the interventional programme at the Kobe site, we conducted an interventional programme of exactly the same content and frequency for the participants of the Osaka site. All of the participants participated in the entire interventional programme schedule and replied to all of the assessment measures.

**Interventional programme**

The interventional programme was mainly structured as Basic knowledge of traumatic brain injury, Methods for coping with cognitive dysfunction and Communication skills training. The operation of the interventional programme was directed by occupational therapists including the author who were schooled in assertiveness training and well-experienced in the rehabilitation of traumatic brain injury patients. Two occupational therapists assisted with the operation of the interventional programme during each session.

1. **Basic knowledge of traumatic brain injury**

   We provided basic information regarding disturbance of attention, memory disturbance, dysexecutive behaviour, and emotional and behavioural changes.

2. **Methods for coping with cognitive dysfunction**

   We provided various coping strategies to family caregivers for the above cognitive dysfunctions, including errorless learning for memory disturbance. Errorless learning allows patients to store information effectively, and immediately correct mistakes when the patient is learning. Memory aids adaptation. We explained how to both adapt memory aids to the needs of the patient, and improve them according to the patients’ conditions. With regard to emotional and behavioural changes, referring to “Assessment and management of behaviour problems associated with traumatic brain injury” by Fonsford, Sloan, and Snow (1995), a method of responding to problematic behaviour of patients utilizing 6 factors was explained: Environmental arrangement, positive enhancement, time out, passive attitude, supportive attitude and records. Environmental arrangement acts to eliminate environmental factors which tend to induce problematic behaviour. Positive enhancement provides a bonus, encourages, praises, and notices when good behaviour is performed. Time-out has the participant ignore the problematic behaviour when it does not stop, leave the room, and isolate the patient. In Passive attitude, criticising, blaming, and pushing or prod-ding must be absolutely avoided. In Supportive attitude always maintain support for the family member. (f) Record a record of problematic behaviour must be maintained in each case.

3. **Communication skills training**

   Assertiveness training followed the standard guidelines and principles suggested by the authors on assertiveness (Alberti & Emmons, 2008). We explained the basis and information of assertiveness training by distributing written information on the subject. Role-playing of assertive behaviour was practiced through coaching and demonstration aids by the directors and other participants. The following roleplay method was suggested to family caregivers to convey their own wants to patients with behaviour problems stress free, while respecting the other person.

   1. Identify the problem behaviour through explaining the situation which gives rise to the problem behaviour of the participants.
   2. Present the request and suggestion which the participant carried out regarding the problem behaviour.
   3. Assign participants to the roles of patient and caregiver. The participants provide information on the patient’s expected response and way of speaking in order for the role playing member to act easily.
   4. Encourage other participants to observe the roleplay and provide positive and negative feedback on the focused objectives of the request and suggestion, the ability to voice feelings, and intention to understand the patient.
   5. Revise the request or suggestion based on the participants and leaders discussion of the contents of the feedback.
   6. Repeat the roleplay taking into account the revised request and suggestion methods.

**Statistical analyses**

SPSS (Statistical Package for Social Sciences v16 for Windows) was used for the statistical analyses. In order to
study the relationship between assertiveness and psychological distress, we conducted regression analysis based on setting the pre-intervention GHQ-30, SDS, and STAI each as dependent variables and RAS as an independent variable. We also conducted repeated measure analyses of variance in order to analyse the variance of variables from pre-intervention, post-intervention, and follow-ups (after three months and after six months) for verification of the effect of the interventional programme. If a significant difference in variance analyses was determined, post-hoc analyses were performed. Tukey’s honestly significant difference test was used for multiple comparisons.

Results

Descriptive information of family participants and patients

Table 1 shows descriptive information of family participants and patients. Family participants consisted of two males and 14 females, between 39 and 75 years of age (M=58, SD=10.5), and 13 were parents and three were spouses. The duration of care giving was between 3 and 19 years (M=10, SD=4.7). The number of other persons living with each family participant and patient was between 0 and 4 persons (M=1.8, SD=1.1), while the numbers of patients living with persons other than the family participant was 13 males and three females. Their ages were between 20 and 50 years old (M=34.4, SD=8.2). The Barthel Index (Mahoney & Barthel, 1965) was used for the functional evaluation of daily living activities of the patients. This 10-item assessment tool evaluates physical dependence in daily living activities. The scoring range of the Barthel Index is between 0 and 100 points and a higher score indicates a greater independence in daily living activities. The Barthel Index of the patients was between 60 and 100 points (M=87.2, SD=14.4).

The relationship between assertiveness and psychological distress

A regression equation called SDS=46.5200.240xRAS was formulated. This regression equation was more significant at $p=0.043$ than the analysis of variance table, and the coefficient of regression was also significant at $p=0.043$. However, the coefficient of determination $R^2$ was small at 0.262 and too low for prediction accuracy. Although a multiple regression analysis was conducted using a forced entry method by entering factors, such as the length of caregiving and the Barthel Index, which were considered to be related ethically, there was no significance at $p=0.255$ in the analysis variance table, and a multiple regression equation, which could be significant, could not be formulated.

Verification of the effectiveness of the interventional programme

1) GHQ-30

The mean score for pre-intervention was 12.63 (SD=8.38), for post-intervention was 7.88 (SD=7.27), after the three-month follow-up was 10.81 (SD=8.72) and after the six-month follow-up was 8.56 (SD=7.77). Although the mean score for post-intervention decreased compared to pre-intervention, it increased again after the three-month follow-up and then again decreased after the six-month follow-up. There was no significant difference

| Participants | Patients |
|--------------|----------|
| Sex | Age | The family relationship with the patients | Length of caregiving | No. of others in home | Sex | Age | Barthel Index |
| F | 53y | Mother | 5y | 2 | M | 24y | 90 |
| F | 57y | Mother | 15y | 2 | F | 29y | 80 |
| F | 61y | Mother | 15y | 3 | F | 32y | 60 |
| F | 59y | Mother | 13y | 3 | M | 30y | 95 |
| F | 50y | Wife | 8y | 1 | M | 50y | 80 |
| M | 49y | Mother | 8y | 2 | M | 26y | 95 |
| M | 68y | Father | 6y | 4 | F | 34y | 100 |
| F | 65y | Mother | 11y | 0 | M | 38y | 85 |
| F | 44y | Mother | 8y | 2 | M | 20y | 65 |
| F | 60y | Mother | 5y | 0 | M | 35y | 100 |
| F | 75y | Mother | 17y | 0 | M | 46y | 100 |
| F | 47y | Wife | 6y | 2 | M | 43y | 90 |
| M | 60y | Father | 11y | 2 | M | 29y | 100 |
| F | 75y | Mother | 10y | 2 | F | 41y | 100 |
| F | 39y | Wife | 3y | 2 | M | 39y | 60 |
| F | 66y | Mother | 19y | 2 | M | 34y | 95 |

Note. M=Male; F=Female.
in the comparison of mean scores ($F=2.217$, $p=0.099$) at the time of measurement (Table 2).

2) SDS
The mean score for pre-intervention was 48.88 ($SD=8.12$), for post-intervention was 44.63 ($SD=7.26$), after the three-month follow-up was 45.19 ($SD=8.72$) and after the six-month follow-up was 44.00 ($SD=9.95$). Although the mean score at post-intervention decreased compared to pre-intervention, it again increased after the three-month follow-up and then again decreased after the six-month follow-up. At the time of measurement, there was a significant difference ($F=2.966$, $p=0.042$) when comparing the mean scores, and the result of post-hoc analysis shows that there was a statistically significant decrease ($p=0.045$) comparing pre-intervention and after the six-month follow-up (Table 2).

3) STAI (Stated anxiety)
The mean score for pre-intervention was 52.88 ($SD=12.18$), for post-intervention was 45.69 ($SD=13.91$), after the three-month follow-up was 49.56 ($SD=14.62$) and after the six-month follow-up was 49.19 ($SD=14.73$). Although the mean score at post-intervention decreased compared to pre-intervention, it increased again after both follow-ups. There was a significant difference ($F=3.538$, $p=0.042$) when comparing the mean scores of pre-intervention and after the six-month follow-up (Table 2).

3) STAI (Trait anxiety)
The mean score for pre-intervention was 55.81 ($SD=11.65$), for post-intervention was 52.94 ($SD=12.11$), after the three-month follow-up was 52.31 ($SD=16.53$) and after the six-month follow-up was 53.06 ($SD=15.40$). Although the mean scores through the time of evaluation after the three-month follow-up gradually decreased, it again increased after the six-month follow-up. There was no significant difference ($F=0.544$, $p=0.655$) comparing the mean scores at the time of measurement (Table 2).

4) RAS
The mean score for pre-intervention was –10.88 ($SD=22.86$), for post-intervention was –7.13 ($SD=27.26$), after the three-month follow-up was –0.56 ($SD=35.14$), and after the six-month follow-up was –8.38 ($SD=25.65$). Although the mean scores through the time of evaluation after the three-month follow-up gradually decreased, it again increased after the six-months follow-up. There was no significant difference ($F=2.450$, $p=0.076$) comparing the mean scores at the time of measurement (Table 2).

## Table 2. Means, SD, and comparison of means—GHQ-30, SDS, STAI, and RAS—pre- and post-intervention and follow-up

|                  | $M$  | $SD$ | $F$     | $p$ value* | $p$ value** |
|------------------|------|------|---------|------------|-------------|
| GHQ-30           | Pre  | 12.63| 8.38    |            |             |
|                  | Post | 7.88 | 7.27    | 2.217      | 0.099       |
|                  | Follow-up (3 M) | 10.81 | 8.72    |             |             |
|                  | Follow-up (6 M) | 8.56  | 7.77    |             |             |
| SDS              | Pre  | 48.88| 8.12    |            |             |
|                  | Post | 44.63| 7.26    | 2.966      | 0.042       |
|                  | Follow-up (3 M) | 45.19 | 8.72    | Pre—Follow-up (6 M) | 0.045       |
|                  | Follow-up (6 M) | 44.00 | 9.95    |             |             |
| STAI (Stated anxiety) | Pre | 52.88| 12.18   |            |             |
|                  | Post | 45.69| 13.91   | 3.538      | 0.042       |
|                  | Follow-up (3 M) | 49.56 | 14.62   | Pre—Post | 0.033       |
|                  | Follow-up (6 M) | 49.19 | 14.73   |             |             |
| STAI (Trait anxiety) | Pre | 55.81| 11.65   |            |             |
|                  | Post | 52.94| 12.11   | 0.544      | 0.655       |
|                  | Follow-up (3 M) | 52.31 | 16.53   |             |             |
|                  | Follow-up (6 M) | 53.06 | 15.40   |             |             |
| RAS              | Pre  | –10.88| 22.86  |            |             |
|                  | Post | –7.13 | 27.26   | 2.450      | 0.076       |
|                  | Follow-up (3 M) | –0.56 | 35.14   |             |             |
|                  | Follow-up (6 M) | –8.38 | 25.65   |             |             |

M=Mean; SD=Standard deviation. * repeated measure ANOVA, ** multiple comparison (Tukey HSD).

Exemplification of the result of the interventional programme

In addition to verification of the effect by statistical analysis, we present here an example of the roleplay and protocol.

1) Presentation of problematic behaviour: a female participant (Person A) experienced stress caused by the behaviour of the patient (the son) who insistently asks her
to listen what has happened today while she was busy cooking dinner.

(2) Presentation of request and suggestion: Person A requested that the son not tell her what has happened during the day while she is cooking dinner.

(3) Role-play: we started the role-play by setting a scene such as cooking dinner.

The cast mate (acting as the son) performed the behaviour of insisting that Person A listen to him based on information such as the patient’s manner of speaking and the patient’s anticipated reaction when hearing Person A’s request and suggestion, and acted out the part of not listening to Person A. The role-play became stalled in a deadlocked situation.

(4) Feedback: other participants gave feedback such as advising Person A to talk to the cast mate (acting as the son) in a calmer manner, and encouraging Person A to be more honest and forthcoming about her son’s behavior. The leader gave feedback to Person A regarding when Person A should make requests of her son that would meet his cognitive function level, such as “Can her son remember her request?” (As her son has memory impairment, there is a possibility that he might forget Person A’s request.)

(5) Modification of request and suggestions: as a result of the discussion of the content of the feedback, Person A modified her request like this. “Until now, I have not had a chance to tell you that I was having a hard time when you begged me to listen to you while I was cooking dinner. Well, I will be able to listen to you after dinner, so please let me listen to you then when I can be relaxed.”

(6) Re-role playing: although the cast mate (acting as the son) acted out accepting Person A’s request, he added some improvised dialogue, such as “I am not confident that I can remember this until tomorrow,” which took into consideration the son’s memory impairment. Therefore, Person A added the suggestion “Shall we put a written promise note in the kitchen just in case you forget?” The cast mate (acting as the son) accepted her suggestion and the role-play ended without them being aggressive to each other.

Person A gave the following feedback after finishing the roleplay: “Although until now I became emotional and often tended to talk aggressively, by performing the roleplay, I could understand what the other person thought after the way I had talked to him. I feel like I can actually present my requests and suggestions to my son, starting tomorrow, after this.” The other participants also gave their feedback based on observing this roleplay. They indicated that they felt all this time, they had only been thinking about and speaking for themselves. And they got a tip on how to present demands and suggestions to a patient. Table 3 shows a selected list of the participants’ demands and suggestions used in the roleplays.

### Discussion

The purpose of this study was to verify the effectiveness of the interventional programme to reduce psychological distress of family caregivers for persons with traumatic brain injury. We focused on the problem of communication between family caregivers of persons with traumatic brain injury and patients with traumatic brain injury. In this study, the interventional programme consisted primarily of communication skills training through assertiveness training. As a result, after a six month follow-up, the mean scores of all psychological distress assessment measures were reduced compared to the pre-intervention mean scores. Through statistical analysis, both SDS, which compared the mean scores between pre-intervention and six months follow-up, and STAI (stated anxiety), which compared the mean scores between pre-intervention and post-intervention, recognised a statistically significant decrease in the mean scores. This indicates that the interventional programme relieved the psychological distress (especially depression and anxiety) of family caregivers of persons with traumatic brain injury. It is characteristic of the results that although the degree
of psychological stress decreased at post-intervention, it tended to increase again at follow-up. Therefore, the results suggest the necessity of continuous support even after finishing the intervention program. We conducted hearings for reference concerning impressions of the interventional programme, and the majority of the participants thought that the interventional programme would be beneficial for many other family caregivers of persons with traumatic brain injury. We also asked for continuous support focussing on each individual participant after finishing the interventional programme. Follow-up counseling for individual participants, including checking how the material learned from the interventional programme is being used in everyday communication with the patient, will enhance the effect of the interventional programme. As was indicated in the exemplification of the effect of the interventional programme, family caregivers who had experienced the interventional programme could objectively monitor their own past communication with the patient by recreating everyday communication exchanges between caregivers and patients through role-playing. This monitoring brought the realization that until now the requests and suggestions to the patient were one-sided and emotional. Furthermore, the monitoring not only improved making requests and suggestions through re-role-playing, it is also surmised that the biggest reason for reducing the psychological distress of family caregivers is that self-efficacy could be built up when necessary, and that one could make adjustments in behaviour and thinking. In this study, RAS was adopted to assess levels of assertiveness. As regression equations could be formulated for pre-intervention RAS and SDS, it is presumed there is a possibility of reducing depression symptoms through assertive communication. The evidence suggests the need for training communication skills, especially assertiveness training in order to reduce the psychological distress of family caregivers of persons with traumatic brain injury. However, although the mean score of RAS increased until the three-month follow-up, there was no statistical significance at the time of measurement. This suggests that a different manner of intervention might be needed for behaviour modification of assertiveness. However, through RAS we see a degree of self-assertion or a trend in communication behaviour, and we believe it was meaningful to adapt the assessment measures in this study.

Study limitation

In the methodology of this study, we have adequately stated the information of the contents of the intervention by using widely acknowledged assessment measures. However, this study is limited due to the small sample size of only 16 persons. The reason the sample size was small was due to the fact that the interventional programme was to be with participants of intended family caregivers in order to extract the frank opinions of the participants. That is to say, patients with traumatic brain injury often need to be watched by others on a daily basis. Therefore, there are many cases where the family caregivers cannot leave home. In order for family caregivers to participate in an interventional programme like the one in this study, family members other than the participant need to take over watching the patient. As a result, it was difficult for family caregivers to participate in the interventional programme. This suggests the necessity of developing human resources, aid agencies and social support services who can monitor the patients. An additional limitation was that due to ethical considerations, there was a lack of a control group. However, the inclusion of a control group would have led to a tendency for the group to only answer psychological assessment measures a total of four times, including the period of six months after the interventional programme, not only before and after the interventional programme. Several researchers have pointed out a lack of scientific validity for not setting a control group in this and previous studies (Boschen, Gargaro, Gan, Gerber & Brandys, 2007; Sinnakaruppan, Downey & Morrison, 2005). This is a common issue of intervention studies, not only studies of family caregivers of persons with traumatic brain injury.

Conclusion

This study suggests that an interventional programme focussing on communication skills training applying assertiveness training is effective in reducing the psychological distress of family caregivers of persons with traumatic brain injury. However, the results of this study suggest that further research taking into account the limitations mentioned previously is necessary.

Acknowledgements: We would like to thank all those carers who participated in this study. Also, we would like to thank the Society for Families with Patients with Traumatic Brain Injury which gave us their cooperation when we were recruiting participants.

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