

FACTORS AFFECTING THE STRESS RESPONSES OF MOTHERS WHO CARE  
FOR A PERSON WITH SEVERE MENTAL RETARDATION AT HOME:  
CAUSAL ANALYSIS USING STRUCTURAL EQUATION MODELING

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# FACTORS AFFECTING THE STRESS RESPONSES OF MOTHERS WHO CARE FOR A PERSON WITH SEVERE MENTAL RETARDATION AT HOME: CAUSAL ANALYSIS USING STRUCTURAL EQUATION MODELING

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## Abstract

The effects of problem behavior of persons with severe mental retardation at home, caregiver burden and positive affect of their mothers as the primary caregivers on the stress responses of mothers were investigated. The results of analysis using structural equation modeling from 20 mothers suggest that problem behavior has an effect on the burden of caregiver mothers and that the care burden enhances stress responses such as anxiety, burnout and depression. These results were confirmed by subjective complaints of mothers obtained from open questions. In contrast, it was also shown that a positive affective state reduced the stress response. Mothers requested participation in parents' associations and utilized facilities for persons with mental retardation. It was suggested that these social resources were useful to reduce the caregiver burden and the stress responses and enhance a positive affective state. However, at present, local welfare services mentioned above are inadequate for persons with mental retardation and their mothers. Therefore, the social support system should be promoted in order to meet these social welfare needs of persons with severe mental retardation and their mothers to assist them.

Key Words : Mental retardation, Problem behavior, Caregiver burden, Stress responses, Positive affect

## I. Introduction

Most persons with mental retardation are classified as "severe"<sup>1)</sup> and approximately 83% of persons with mental retardation at home live with their family, i.e., parents<sup>2)</sup>. The primary caregiver is usually their mother<sup>3)</sup>. It has been reported that these caregivers have problems, including care burden<sup>4)</sup>, stress<sup>5)</sup>, chronic fatigue<sup>4) 6)</sup> and sorrow<sup>7)</sup>, and it is indicated that these family caregivers should be supported by social welfare services<sup>7)</sup>.

One of the leading models explaining the burden of family caregivers is Lazarus's cognitively oriented theory of stress<sup>8)</sup>. This theory explains that the caregiver burden, a negative cognition, is caused by

stressors, including problem behavior of persons with mental retardation<sup>9) 10)</sup> and activities of daily living (ADL), leading to stress responses, such as anxiety, depression and burnout<sup>5)</sup>. On the other hand, the primary caregivers, i.e., the mothers, are related to the care recipients, their children. Therefore, in addition to the above described negative affective state they also have a positive one, i.e., mental support<sup>11)</sup> and happiness<sup>12)</sup> that can be derived from having their own child. Previous studies on persons with mental retardation have reported the association of problem behavior, a stressor, with caregiver burden<sup>9) 10)</sup> and that of the stress responses with care burden<sup>4)</sup> and positive affective state<sup>11)</sup>, but there has been no

empirical study on the effect of stress-derived caregiver burden on the stress responses based on the cognitively oriented theory of stress.

The objective of this study was to comprehensively analyze the causal relationships such as the effects of problem behavior and ADL of persons with severe mental retardation at home on the care burden of their mothers as the primary caregivers, and the effects of care burden and the positive affective state of their mothers on mothers' stress responses, including anxiety, burnout and depression. In addition, to obtain some idea for support measures to their mothers, an open question was included to understand their stress and their requests to the government and community, which cannot be identified using a questionnaire study. Based on the above, we evaluated the interrelationship between the results of quantitative and qualitative analyses and propose social support measures for mothers.

## II. Methods

### 1. Subjects

The subjects surveyed were 23 persons with mental retardation at home and their primary caregivers in A city in Aomori with a person with mental retardation at home categorized as Grade A in mental retardation certificate (Ryoiku Techo), based on the criteria of an intelligence quotient (IQ) of 35 or less, or IQ of 50 or less and physical disability grade of 1 to 3. The subjects were selected on the basis of their introduction from general welfare center for people with mental retardation, day sheltered workshops for physically disabled persons and people with mental retardation and rehabilitation facilities for people with mental retardation in Aomori. This study was approved by the ethics committee of Aomori University of Health and Welfare (approved on June 13, 2001). The subjects analyzed included 20 families who provided oral and written informed consent in accordance with the rules of the ethics committee and signed the agreement on participation in this study. The study period was one month from

March to April 2002. The details of the subjects analyzed are shown in Table 1.

Table 1 Characteristics of subjects

Sex of care recipients	
Male/Female	9 (45.0)/11 (55.0)
Age of care recipients (years)*	22.3±7.57 (6-32)
Complications	
None	8 (40.0)
Autism	3 (15.0)
Epilepsy	8 (40.0)
Down syndrome	1 (5.0)
Age of primary caregivers (years)*	49.8±8.64 (32-63)
Relationship of primary caregivers	
Mother	20 (100.0)
Occupation of primary caregivers	
Housewife	15 (75.0)
Part-time worker	4 (20.0)
Self-employed business	1 (5.0)
Care duration (months)*	269.0±92.26 (80-394)
Alternative caregivers	
None	4 (20.0)
Father	11 (55.0)
Sibling	5 (25.0)
Attendance to facilities†	
Yes/No	13 (65.0)/7 (35.0)
Short stay‡	
Yes/No	13 (65.0)/7 (35.0)
Participation in a parents' association	
Yes/No	19 (95.0)/1 (5.0)

Figures in parenthesis indicate the percentage. \*Mean ± Standard deviation (Min. - Max.). †Attendance at a school for people with mental retardation, sheltered workshop for people with mental retardation, rehabilitation facilities for people with mental retardation and day sheltered workshop for physically disabled persons, and utilization of day care services at the time of the survey. ‡Utilization of short-term stay facilities at the time of the survey. n=20.

### 2. Survey method and items

A physiotherapist interviewed the primary caregivers at their home and asked them to rate their responses using scales and respond to the questionnaires. The survey items consisted of the background profile of the care recipient and family caregiver, ADL and problem behavior of the care recipient, burden of the primary caregiver, stress response, i.e., anxiety, depression, burnout, positive affective state of the primary caregiver, and their requests to the government and community.

The ADL of the care recipients was rated using the extended ADL scale (EADL scale) of Hosokawa et al.<sup>13)</sup> based on the description from the primary caregiver. The EADL scale consists of 8 basic ADL (BADL) and

4 instrumental ADL (IADL) items. The BADL includes 8 activities of feeding, moving from the wheelchair to bed and return, personal toilet (washing the face, combing the hair, shaving, cleaning the teeth), getting on and off the toilet, bathing self, walking on a level surface (or if unable to walk, propel a wheelchair), ascend and descend stairs and dressing. The IADL includes 4 activities of outing by bus and train, purchase of daily necessities, meal preparation and deposit to and withdrawal from a bank account. The BADL and IADL are evaluated by two grades, "independent" and "assisted or incapable", with the higher score indicating the higher ADL (0 to 12 points). The problem behavior of care recipients was evaluated using the Motivation Assessment Scale (MAS)<sup>14)</sup>. This scale consists of 4 subscales, "Sensory", "Escape", "Attention" and "Tangible" on a 7-point scale and a higher score indicates marked problem behavior (0 – 96 points). The caregiver burden was measured using the revised Cost of Care Index (CCI) of Kosberg et al.<sup>15)</sup>, which is revised for caregivers of persons with mental retardation at home by Ogata et al.<sup>16)</sup>. The CCI consists of 5 subscales, "personal and social restrictions", "physical and emotional problems", "value investment in caregiving", "perception of the care recipient as a provocateur (hereinafter unpleasantness)" and "economic costs" on a 4-point scale and a high score indicates heavy burden of the caregivers (20 to 80 points).

The anxiety was measured using the State-Trait Anxiety Inventory Form JYZ (STAI)<sup>17)</sup> which is a Japanese version of the State-Trait Anxiety Inventory Form Y of Spielberger<sup>18)</sup>, which was translated and revised for Japanese by Hidano et al. Of the inventory form, 20 subscales for trait anxiety, indicating the trait that the subject was prone to be anxious about, were used. The subscales are rated on a 4-point scale and a high score indicates the anxiety trait (20 to 80 points). Depression was measured using the Japanese translated version<sup>19)</sup> of the Center for Epidemiologic Studies Depression Scale (CES-D)

of Radloff<sup>20)</sup>. The scale is on a 4-point scale and a high score indicates the depression trait (0 to 60 points). Burnout was measured using the revised scale for Japanese by Munekata et al.<sup>21)</sup> (hereinafter burnout scale) based on Pines's original scale. The scale is rated on a 2-point scale and a high score indicates the burnout trait (0 to 20 points). Positive affective state was measured using 19 scales on "mental state" from the WHO Subjective Well-Being Inventory (SUBI)<sup>22)</sup>. The inventory consists of 7 subscales, "Subjective well-being positive affect", "Expectation-achievement congruence", "Confidence in coping", "Transcendence", "Family group support", "Social support" and "Primary group concern" on a 3-point scale and a high score indicates the trait of positive affective state (19 to 57 points).

In this study, the psychological state of caregivers that could not be determined by the assessment scales was evaluated using a structured interview to the caregivers. The following questions were posed: 1) "Please tell us about your care-related problems, troubles and anxieties" (hereinafter Problems/Troubles), 2) "Please tell us about events supporting you, your anticipation and fulfillment, and issues with positively coping" (Supportive events) and 3) "Please tell us about your requests to the government and community" (Requests to the government and community).

### 3. Analysis method

The causal hypothesis among caregiver stressors, caregiver burden, stress responses and positive affective state was tested using structural equation modeling (SEM). The constructs, [Problem behavior of persons with mental retardation], [Mother's care burden], [Mother's stress response] and [Mother's mental sanity] were selected as latent variables and scores of the corresponding scales were considered to be observed variables. A multiple indicator model of the SEM was constructed with a causal pathway for the indirect effect of [Problem behavior of persons with mental retardation] on the [Mother's stress

response] through the [Mother's care burden] and a direct effect of the [Mother's mental sanity] on the [Mother's stress response] (Figure 1). Factor means of the latent variables can be biased by EADL score, age of care recipients and their mothers. Therefore, the influence on these variables was adjusted. When a single indicator was used, the error variance was estimated in accordance with the following equation and fixed.

$Se^2 = (1-\rho)Sx^2$   $Se^2$ : error variance,  $\rho$ : Cronbach's  $\alpha$  of scale,  $Sx$ : standard deviation of scale

Considering the small sample size and non-normal distribution of the data, the maximum-likelihood method was used. Simulation was conducted in 1000 samples using bootstrapping techniques to correct for non-normality and bias due to the small sample size and estimate the standard error of estimated values and bias.

Responses to open questions were recorded after obtaining consent from the subjects and saved on the

computer as text data. In analyzing the data, analysis software for text data was used to eliminate the contamination of the subjective explanation by analyzers in coding responses. The analysis procedures were as follows: 1) responses to open questions in text format were rewritten with spaces separating the words; 2) words were extracted in the threshold of 2, and 3) Three scales of stress responses were categorized into following groups to investigate the relationship between the stress responses and responses to open questions and the significance was tested to determine characteristic responses in each group. In analysis of the STAI score, female subjects with a score of 50 or more were classified into the anxiety group, based on the profile criteria in the assessment manual. In analysis of the CES-D score, persons with scores of 16 points or more were considered to have depressive characteristics (Depression group)<sup>23)</sup>. Subjects with a burnout scale of 5 points or more were classified into the Burnout group<sup>24)</sup>.

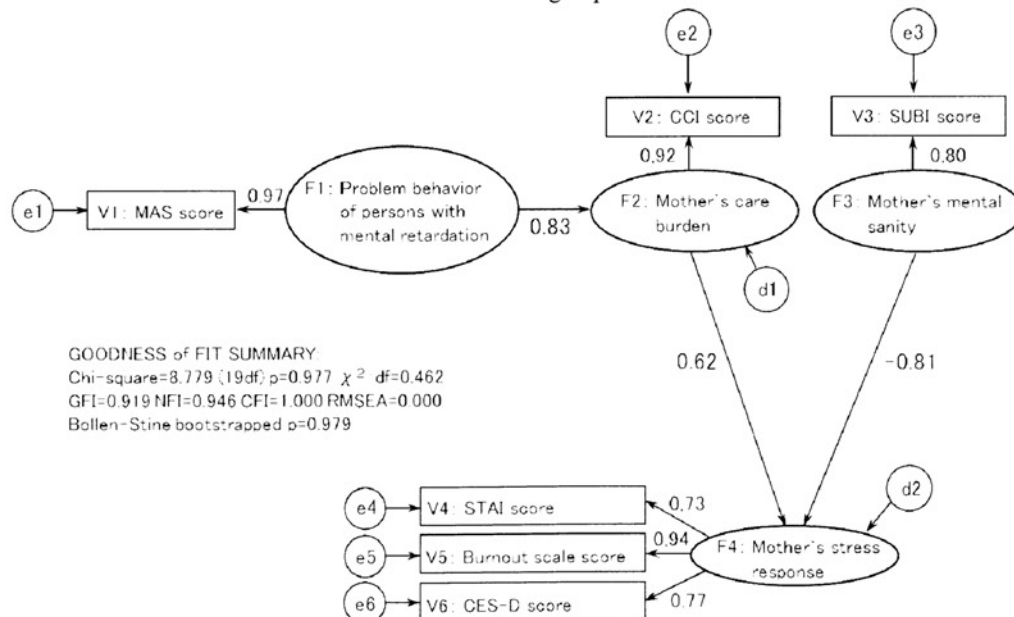


Figure 1 Effects of problem behavior, caregiver burden and mental sanity on stress responses of mothers who care for a person with mental retardation

The results are adjusted for the ADL score, the age of persons with mental retardation, and the mother's age. All figures represent standardized solution. All causal coefficients and effect indicators were significant ( $p < 0.01$ ).  $n=20$ . F: latent variable, V: observed variable, d: disturbance variable, e: error variable. GFI: Goodness of Fit Index, CFI: Comparative Fit Index, RMSEA: Root Mean Square Error of Approximation. Covariances between error variables are omitted.

Statistical analysis was conducted using SPSS 10.0J Base System and Amos 6.0 and the significance of responses to open questions was tested using Word Miner ver. 1.00 (Japan Information Processing Service Co.,Ltd.).

### III. Results

#### 1. Scale scores

Table 2 Scale scores

	Full point	Median (25, 75 percentile values)	Min. - Max.
EADL			
Self-care activities	5	0.00 (0.00, 1.75)	0-3
Locomotion activities	3	3.00 (2.00, 3.00)	0-3
Instrumental ADL	4	0.00 (0.00, 0.00)	0-0
Total score	12	3.00 (2.00, 3.75)	0-6
Motivation assessment scale			
Sensory	24	10.50 (6.25, 19.00)	0-25
Escape	24	8.00 (2.25, 12.75)	0-15
Attention	24	10.50 (3.25, 16.75)	0-24
Tangible	24	9.00 (3.00, 14.75)	0-17
Total score	96	35.00 (14.25, 59.25)	5-72
Cost of care index			
Personal and social restrictions	20	10.50 (9.00, 14.00)	5-16
Physical and emotional health	20	10.00 (10.00, 12.75)	7-16
Value investment in caregiving	20	5.50 (4.00, 7.70)	4-9
Unpleasantness	20	9.00 (8.00, 11.00)	4-14
Economic costs	20	8.50 (8.00, 10.00)	5-13
Total score	80	45.00 (40.00, 52.00)	25-58
STAI	80	51.00 (39.00, 55.75)	28-58
Burn out scale	20	5.00 (1.25, 9.75)	0-11
CES-D	60	19.00 (14.00, 22.00)	8-25
SUBI: Mental sanity			
Subjective well-being positive affect	9	6.00 (4.00, 6.00)	3-9
Expectation achievement congruence	9	5.00 (5.00, 6.00)	4-7
Confidence in coping	9	6.00 (6.00, 7.00)	6-9
Transcendence	9	6.00 (4.25, 6.00)	4-8
Family group support	9	7.00 (5.25, 7.75)	3-9
Social support	9	6.00 (4.25, 7.75)	3-9
Primary group concern	3	2.00 (2.00, 2.00)	2-3
Total score	57	37.50 (33.25, 40.75)	31-52

EADL: Extended activities of daily living scale of Hosokawa et al. SUBI: The subjective Well-being Inventory. STAI: State-Trait Anxiety Inventory-Form JYZ. CES-D: The Center for Epidemiologic Studies Depression Scale. n=20.

The characteristics of the subjects are shown in Table 1. All of the primary caregivers were mothers. The descriptive statistics of the scales are shown in Table 2. The IADL score in the EADL scale was 0 points for all subjects; consequently, the median total score was decreased to 3.00 points with a small interquartile range. Therefore, it was indicated that all of the subjects required assistance based on the IADL and most of them also required help based on several BADLs. To be specific in BADL by item, the median score of self-care activities (feeding, personal toilet, getting on and off the toilet, bathing self, and dressing) was 0 points, on the other hand, the median score of locomotion activities (moving from wheelchair to bed and return, walking on a level

surface and ascending and descending stairs) was full points. Therefore, most subjects required assistance for self care although they were independent in locomotion activities.

The median MAS and ICC were high in score, 35.00 and 45.00, respectively; suggesting that the subject persons with mental retardation exhibited problem behavior and that their mothers, the caregivers, had burden of care.

In the scales for stress response, the median scores of the STAI, the burnout scale and the CES-D were higher than the above-mentioned cut-off values. Consequently, 12 (60.0%) of the subject mothers were classified into the Anxiety group, 13 (65.0%) into the Depression group, 11 (55.0%) into the Burnout group, and 11 (55.0%) into the Anxiety-Depression-Burnout group and more than half of them had great stress responses.

The median SUBI score was 37.50 and the minimum was 31. Scores of this scale of less than 31 points indicate a tendency towards a low positive affective state<sup>22)</sup>, therefore, none of the mothers had a low positive affect.

#### 2. Causal relationship among stressors, caregiver burden, stress responses and positive affect

In constructing a causal model in SEM, both [problem behavior of persons with mental retardation] and [EADL] were first established as having a direct effect on [mother's care burden] for analysis. However, effect indicator of [EADL] was not significant. In addition, as described above, scores of the EADL scale were similar among subjects. Consequently, [EADL] was included in the model as a moderator variable but not as an exogenous variable. The analysis results of SEM are shown in Figure 1. The direct effect of [problem behavior of persons with mental retardation] on [mother's care burden] was 0.83 and that of [mother's care burden] on [mother's stress response] was 0.62. An indirect effect is defined as the product of related direct effects.

Consequently, the indirect effect of [problem behavior of persons with mental retardation] on [mother's stress response] through [mother's care burden] was 0.51. The direct effect of [mother's mental state] on [mother's stress response] was -0.81.

The goodness of fit measures were appropriate and the established causal model fitted well to the data. All effect indicators and all causal coefficients

between each latent variables were significant ( $p < 0.01$ ) using the Wald test. Furthermore, in application of the Bollen-Stine bootstrap for goodness of fit measures, the p-value was higher than 0.05, showing a good fitness to the model. Since all effect indicators were 0.7 or more, it was considered that the association between the constructs and observed variables was properly established.

Table 3 Problems and troubles, supportive events, and requests to the government and community for mothers

Response	Group				
	Anxiety group (n=12)	Depression group (n=13)	Burnout group (n=11)	Anxiety × Depression × Burnout group (n=11)	Non-Anxiety × Depression × Burnout group (n=7)
Problems and troubles					
Concerns about future	○	○	○	○	○
Transportation is difficult.	○	○	○	○	
I feel at a loss when I am in poor health.	○	○	○	○	
Supportive events					
Parents' association	○	○	○	○	○
Presence of my child					○
Hobby					○
Requests to the government and community					
Home care helper	○	○	○	○	○
Assistance with transportation	○	○	○	○	○
Quality of facilities					○

n=20. ○:  $p < 0.05$

### 3. Results of open questions

The details of the mothers' problems/troubles are shown in Table 3. Responses with significance were "Concerns about the future", "Transportation is difficult" and "I feel at a loss when I am in poor health" in the Anxiety, Depression, Burnout and Anxiety-Depression-Burnout groups, while "Concerns about the future" in the Non-Anxiety-Depression-Burnout group. The detailed "Concerns about the future" included "I want to live together with my child but I have no other choice but to put my child into care facilities" and "I want to live together with my child as long as possible, but I have concerns about the future." In addition, "Child care effects our business" was pointed out by 1 (5.0%), "People look at us dryly" by 3 (15.0%), "Child's obesity" by 2 (10.0%) mothers, "We cannot go out anywhere, even on holidays" by 2 (10.0%),

"An extended parents' association cannot meet parents' needs" by 2 (10.0%), "Toilets in public facilities are not friendly towards persons with disabilities" by 1 (5.0%), "Problem behavior, such as panic and aggression" by 1 (5.0%). The support system will be revised and the resources can be chosen but there is no option" by 2 (10.0%), "There are few consultation services" by 1 (5.0%), and "I was sometimes accused in the parents' association. It is difficult to join an extended association" by 1 (5.0%).

The details of the mothers' supportive events are shown in Table 3. Responses with significance were "Parents' association" in the Anxiety, Depression, Burnout and Anxiety-Depression-Burnout groups while "Parents' association", "Presence of my child" and "Hobby" were significant in the Non-Anxiety-Depression-Burnout group. "Parents' association" included "My system of values has



changed”, “People surrounding us understand us”, “I exchange information”, “I learn so much from listening to others”, “I am very satisfied daily with the parents’ association” and “I learn my way of life” The contents of “Presence of my child” were “My child allowed me to get to where I am now” and “When I see my child’s sleeping face my burden goes away.” In addition, “Walking” was pointed out by 2 (10.0%), “Shopping” by 2 (10.0%), “I am attempting many means of communication” by 1 (5.0%), “I am studying psychology related to well-being at a correspondence college” by 1 (5.0%), “Outing” by 2 (10.0%), “My mother and sister” by 1 (5.0%), and “Pet” by 1 (5.0%).

The details of the mothers’ requests to the government and community are shown in Table 3. Responses with significance were “Home care helper” and “Assistance with transportation” in the Anxiety, Depression, Burnout and Anxiety-Depression-Burnout groups while “Home care helper”, “Assistance with transportation” and “Quality of facilities” in the Non-Anxiety-Depression-Burnout group. In addition, “An easy-to-use facility is helpful” was pointed out by 1 (5.0%), “I want a facility that always provides medical treatment” by 1 (5.0%), “I’d like to have communication with volunteers” by 2 (10.0%), “Instruction methods are different in each facility. I’d like professionals to use the same method although they have different opinions” by 1 (5.0%), “An easy-to-use and friendly consultation institution is helpful” by 2 (10.0%), and “It is better that facilities are located in downtown, not suburbs” by 2 (10.0%).

#### IV. Discussion

In this study, the Ryoiku Techo was used to classify the subjects by the grade of mental retardation. The Ryoiku Techo was adopted as the criteria for the following reasons: 1) the criteria for “Grade A” in this system considers both the intellectual level and the severity (level) of the physical disability; 2) the severity of the disability was previously assessed by specialists; 3) the Ryoiku Techo is based on the

comprehensive assessment of intellectual level, social ability and the ability for activities of daily living; and 4) persons with mental retardation are actually identified by the Ryoiku Techo in Japan. Other classifications for mental retardation include the notification of the former Japanese Ministry of Education, Science, Sports and Culture and the Definition by the American Association on Mental Retardation and the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. However, these classifications were considered inferior to the Ryoiku Techo as tools for assessing the level of mental retardation in this study: 1) the severity of physical disability is not considered; 2) subjects are required to respond to many detailed questions to achieve functions of the original multi-axial diagnostic system, resulting in significant effort on the part of the subjects; 3) specialists alone who are eligible to assess are allowed to assess and non-specialist are not restricted in the use; 4) the severity of mental retardation is not classified as “Severe”, which is necessary for this study; and 5) the criteria for disability are indefinite and it is difficult to assess subjects.

The reasons for adopting the measuring scales used in this study are described below. The EADL scale of Hosokawa et al.<sup>13)</sup> is an integrated scale consisting of BADL items of the Barthel Index, which is considered the most popular and reliable index in rehabilitation, and IADL items. The ADL ability of persons with severe mental retardation at home is expected to range from BADL to IADL. The ADL level from BADL to IADL can be measured easily with one scale and estimate activities that they can and cannot do, because this scale is a single-directory scale. MAS<sup>14)</sup> is a scale that was developed to evaluate the function of problem behavior of persons (children) with mental retardation. MAS is a rare scale, which has been confirmed as being reliable and valid in persons (children) with mental retardation. Many studies in persons (children) with mental retardation world-wide have used the MAS to evaluate



variables that are dependent upon problem behavior and to provide interventions for problem behavior. The Cost of Care Index <sup>15)</sup> developed by Kosberg et al. evaluates care burden from many aspects. This is a highly reliable and valid scale to analyze the effects and difficulties that caregivers are and could be given, to determine a problem-solving approach and provide appropriate support. The level of care burden indicated by this scale reflects the interrelationship between the severity of disability in general daily activities and mental disorder, including behavioral disorder, as well as the problems of both the care recipients and caregivers. This scale is used in various programs to understand potential care problems. The CCI <sup>16)</sup> used in this study is the Japanese version that was modified from this scale and is specific for family caregivers of persons with mental retardation. The English version of STAI (Form Y) <sup>18)</sup>, is the most basic scale for the measurement of anxiety and is commonly used world-wide. The trait anxiety is a relatively stable individual trait that is relatively independent of the measurement conditions. Consequently, it is useful to select groups with different level of anxiety. This scale is commonly used in studies of anxiety in clinical practice because it measures and differentiates the trait of anxiety. The STAI used in this study (Form JYZ) <sup>17)</sup> consists of items relevant to the Japanese culture and differentiates between two components of anxiety, i.e., negative emotion indicating the presence of anxiety and positive emotion indicating the absence of anxiety. Therefore, the Japanese version is considered superior to the original version. The CES-D <sup>20)</sup> was developed by the UN national institute and has been confirmed to have sufficient reliability and validity for the assessment of depression. The CES-D is the most popular scale for the assessment of depression world-wide and is used to assess depression as the stress response of caregivers at home in this study. The Pines Burnout Measure <sup>21)</sup> is an internationally leading scale for the assessment of burnout. This

scale was developed in subjects including Japanese patients and its reliability and validity has been confirmed. Mothers of persons with mental retardation, i.e., the primary caregivers, are considered to exhibit symptoms of physical, mental and emotional exhaustion, i.e., burnout, to varying degrees as a consequence of the psychologic energy expended during the long-term support process. These caregivers exhibit physical as well as psychological and mental fatigue. This scale was developed based upon the concept of burnout and consists of subscales to measure the above three concepts. The SUBI <sup>22)</sup> consists of 7 subscales of mental health, as described above. Mothers of persons with mental retardation, i.e., primary caregivers, exert both negative and positive effects that are generated by their interactions with their children. These subscales have been designed based on multiple concepts, including positive affect, confidence in coping, expectation-achievement congruence, transcendence, and the family group and social support. Therefore, this inventory appropriately indicates positive affect specific to the mothers. Furthermore, negative affect does not always correlate with positive affect and the two conflicting affects can act independently. Even under stressed conditions, which can generate negative affect, people can have fulfilling life if they experience an overall positive affect. Therefore, stress care requires the assessment of mental health as well as negative affect. It is necessary to assess positive and negative affects independently when establishing measures to cope with stress. The SUBI is an appropriate index for this negative affect.

In this study, the possibility was suggested that problem behavior has an effect on the burden of caregiver mothers and that the care burden enhances stress responses, such as anxiety, burnout and depression. These results were confirmed by subjective complaints of the mothers obtained from open questions. In contrast, it was also shown that a positive affective state reduced the stress response. Mothers also wanted to utilize parents' associations,

home care helper, and assistance with transportation for persons with mental retardation. It was suggested that these social resources were useful to reduce caregiver burden and stress responses and enhance a positive affective state.

Stress responses of mothers that were shown in previous studies included anxiety and depression due to difficulties with care and treatment, and inadequate support of the child after death of the parents<sup>7) 25)</sup>, anxiety about low developmental potential, difficulties in communication and social adjustment<sup>25)</sup> and burnout due to burden of care<sup>4)</sup>. Also in this study, the mothers' problems/troubles were "Concerns about the future", "Transportation is difficult" and "I feel at a loss when I am in poor health" in the Anxiety, Depression, and Burnout groups, which corresponded to the above study results. Furthermore, more than half of the mothers had great stress responses, such as anxiety, depression and burnout. Therefore, such a constant negative mental state deriving from caregiver burden could induce a stress response.

It is difficult to eliminate problematic behaviors of persons with mental retardation as they grow<sup>26)</sup>. However, it has been reported that the caregiver burden and the stress responses induced by the stressor can be reduced by appropriate personal social support<sup>4) 6) 12)</sup>. Mothers place much importance on the parents' association for personal social support<sup>11)</sup> and it has been reported that many mothers had a relation to a parents' association<sup>6)</sup>. Also in this study, the percentage of mothers belonging to a parents' association was high (95%) and the mothers in the Anxiety, Depression and Burnout groups reported a parents' association as psychological support. These results confirmed the necessity and importance of a parents' association. The parents' association is a self-help group that is established by voluntary gathering of persons who are in the same situation and many researchers have indicated that these groups are useful in supporting caregiver mothers<sup>27)</sup>. The advantages of participation in a parents' association include sympathy of the caregiver burden, sharing of

knowledge on care, and development of the concept of mutual assistance<sup>11) 27)</sup>. It plays an important role in the psychological support and stability of mothers<sup>7) 11)</sup>.

Mothers also requested full social support in facilities that they currently utilize. Stress responses of the mothers, such as anxiety, depression and burnout can also be induced from concern about whether their child will live independently with appropriate support in facilities that they currently utilize<sup>7)</sup>. The results of this study showed "Quality of facilities" and "Assistance with transportation" as requests to the government and community. Previous studies<sup>1) 3)</sup> have shown that many mothers selected facilities that they currently utilize as a living place when persons with mental retardation become old or as the final place, which was consistent with the results of this study. Many mothers desired that their children would live in a similar circumstance to the current one without changes or restrictions also in their middle age and until the end of their life<sup>1)</sup>.

On the other hand, the results of this study confirmed the effect of the mother's mental sanity on the stress responses and the effect level was similar to that of the caregiver burden on the stress responses. It suggests the possibility that a positive affective state of the mothers can reduce the stress responses even though they are induced by caregiver burden. Previous studies pointed out that mothers recognized a positive affective state which was obtained mentally supported by their child, such as happiness, i.e., "mothers obtain self-recovery only from coping with the status of their child with courage and recognizing positive social meaning"<sup>25)</sup>, "mothers gain their identity with care of their child and satisfy themselves"<sup>27)</sup>, and "addition of positive meaning such as confidence as a parent that mothers go together with their child with unflappability and expression of affection between mothers and their child"<sup>28)</sup>. The results of this study also confirmed the above findings with the responses of "Presence of my child" as a psychological support for the mothers. In this study, these positive affective states had some

effect on the scores of the SUBI scales. The possibility was suggested that these positive affective states reduced the stress responses<sup>4) 9)</sup>, consistent with the results of this study. Many parents participating in a parents' association experienced such positive affects as discovery of new hope<sup>29)</sup>. Mothers dispel self-denying thoughts derived from mental damage when they participate in a parents' association, talk together with parents who are thinking and living in the same situation, and gain a positive vision with hope from peer counseling that allows other to listen and respond to their experiences with loneliness and hopelessness<sup>7) 27) 28)</sup>.

The general findings of this study from the aspect of health and welfare sciences are described below. Previous studies discretely discussed the relationship between each of the factors for problem behavior, burden of caregivers, stress response and positive affects. Consequently, the comprehensive relationship between these factors was assumed. In this study, these factors were incorporated into one causal model in SEM, as latent variables, and the analysis results using this model confirmed that the cognitively oriented theory of stress<sup>8)</sup> also including the influence of positive affects fit with the primary caregiver mothers. In addition, stress responses, i.e., anxiety, depression and burnout exhibit different developmental processes and should be dealt with using countermeasures considering these psychological traits<sup>4) 7) 25)</sup>. Therefore, the subjects' responses were analyzed using the stress responses-categorized subject groups in this study. Consequently, problems were interpreted considering the psychological traits of the mothers and appropriate measures were designed.

The results of this study indicated that all subjects in these categorized groups required association with the parents, home care helper and assistance with transportation. Therefore, these social supporting measures should be established and improved. Furthermore, it was shown that improved social resources relieved the burden and stress response of

caregiver mothers. An earlier study also supported these results<sup>4)</sup>. By contrast, the Mental Retardation: Definition, Classification, and Systems of Support of the American Association on Mental Retardation<sup>30)</sup> proposed the need for the social support of mothers. However, this system also indicated that such support should be provided considering the interaction with the environment of their daily lives. It also pointed out that support for mothers depended upon the types of difficulties they faced, insufficient support resources and psychologists who had experienced a supporting approach<sup>1) 3) 7)</sup>. Therefore, supporting resources, including the patients' associations, home care helper and assistance with transportation should be provided with correspondence with the individual environment and practical demands of the mothers. Thus, experienced psychologists to support them should be trained as soon as possible.

For example in practical measures for the parents' association, it was pointed out a hierarchical and perfunctory organization in a parents' association, value gaps among the mothers' generations, inflexible association system and burden of communications among mothers<sup>11)</sup> can further contribute to the parent's difficulties. Therefore, social support is needed to correct these negative aspects and develop a parents' association that provides peer counseling, as an original function.

In this study, EADL was not appropriate as an exogenous variable for the burden of the caregivers. Consequently, it was included in the causal model as a moderator variable. It was suggested that EADL was not a significant effect indicator in SEM because the total score and scores of the subscales showed a floor or ceiling effect. However, none of the subjects were independent in IADL and most of them required assistance in self care and exhibited a similar score pattern. A previous study indicated the necessity of care in bathing, toilet, face washing and hair styling<sup>1)</sup>, which supported the findings of this study. Tsai et al.<sup>6)</sup> showed that ADL of persons with mental retardation affected the stress of their mother. Therefore, it is

necessary to evaluate the effect using more sensitive ADL-rating scales to measure BADL of persons with mental retardation.

The results of this study cannot be generalized due to the non-random selection of subjects within a limited region. However, all eligible persons in facilities participating in the study were included among the subjects surveyed. Therefore, it is considered that the results indicated the actual conditions of these subjects. Further studies should be conducted to evaluate a larger number of subjects in other regions using SEM with a model with time-dependent latent variables.

**Note:** The Ryoiku Techo is issued to provide consistent instruction and consultation for persons with mental retardation and to facilitate the support of different welfare systems. The Ryoiku Techo system is managed by local government in accordance with the notification of the Ministry of Health and Welfare of 1973. The grade of mental retardation is comprehensively assessed by consultation with the office for rehabilitation of persons with mental retardation and the child consultation office from both aspects of intellectual level and actual conditions in daily and social life. The criteria for mental retardation are as follows: Severe (A): a person with intelligence quotient (IQ) of 35 or less (a person physically handicapped, blind or deaf mutism: IQ of 50 or less) who meets either of the following conditions: 1) a person requiring assistance in daily life, including meal, dressing, toilet and face-washing; 2) a person who has problem behavior including incontinence, pica, excitation and akinesia and always requires attention and instruction. Other: a person who does not meet the criteria for severe grade.

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