Perceptions of the Caregiving Role among Mothers of Children with Severe Motor and Intellectual Disabilities and its Impact on the Mothers’ Well-being

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Abstract

This research sought to examine the structure of “perceptions of the caregiving role” among mothers caring for children with severe motor and intellectual disabilities and clarify the impact of these “perceptions of the caregiving role” on the well-being of the mother. Subjects were 154 mothers receiving a questionnaire for mothers of children with severe motor and intellectual disabilities residing in the suburbs of Tokyo. Results of analysis indicated the following. Five factors were identified with regard to the structure of “perceptions of the caregiving role”: “being solely responsible for the role,” “primacy of the caregiving role,” “maximization of role involvement,” “recognition of personal gain,” and “role captivity.” Of these, those factors having a significant impact on the well-being of the mother were “being solely responsible for the role,” “recognition of personal gain,” and “role captivity.” Among these impacting factors, “role captivity,” i.e. being constrained by perceptions as part of norms regarding fulfillment of the caregiving role, had the greatest impact on well-being and resulted in indirectly diminishing well-being through the reduction of social support overall and amplification of secondary stressors.

Key Words

Children with Severe Motor and Intellectual Disabilities, Mothers, Well-Being, Perceptions of the Caregiving Role, Role Captivity

I. Introduction

As a result of the increased prevalence of the principle of normalization or the shift in welfare policy from facilities to communities, the number of children and individuals with disabilities who, despite being severely disabled, seek to live at home in the local community has increased. The current reality, however, is not as promising. To start with, the increasing severity of disability has been noted. In addition, among children with severe motor and intellectual disabilities (SMID) living at home, the number of those requiring a variety of medical care, such as nasogastric tube feeding, suction, oxygen inhalation, tracheostomy care, and home mechanical ventilation, has increased. Moreover, the family burden has also increased because of the increasing sophistication and complexity of such care.

Thus, this study focused on families of children with SMID and particularly mothers, who are often responsible for the everyday care of the child. Numerous studies on the well-being and stress of families with a disabled child have been previously conducted based on the cognitive model of stress and coping (Lazarus & Folkman 1984; Nakagawa 2003a). With regard to the relationship between the type and extent of the child’s

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disability and the family’s stress level, for example, greater caregiving demand and more severe disability have been found to result in a higher stress level for the family and increased level of depression for the mother (Harris & McHale 1989); with regard to social support, spousal support in particular is most effective at reducing a parent’s stress (Barbarian et al. 1985). In addition, problem-focused coping such as cognitive restructuring, information seeking, seeking social support, confrontation, and planful problem solving has been found to reduce a parent’s stress while emotional-focused coping such as wishful thinking, escape-avoidance, self-blame, distancing, self-controlling, and accepting responsibility amplifies a parent’s stress (Miller et al. 1992).

The current study examines “perceptions of the caregiving role” as a factor affecting the well-being of mothers of children with SMID and studies the impact these perceptions have on well-being. This term refers to the perceptions that the individual responsible for the caregiving role has the individual’s involvement in the caregiving role, how the individual fulfills that role, and the nature of those perceptions is largely related to the well-being of the individual responsible for providing care.

Research on the perceptions and attitudes towards care of mothers of children with a disability or chronic illness has not proceeded systematically, but the following previous studies do exist. They found that mothers subordinate their lives to that of the child, sacrificing themselves for the child and changing their lifestyles to adapt to this new role (Guerriere & McKeever 1997), that mothers express a great deal of love towards the child, value their relationship with the child, and look for reward in caring for that child (Larson 1998), and that mothers of a child with cancer constantly attempt to be physically near the child in order to reassure and comfort that child (Young et al. 2002). Based on a study of attitudes of families caring for an adult with a mental or physical disability or an elderly family member, Twigg and Atkin (1994) identified 3 types of caring: in the engulfment mode, a family member subordinates their lives to that of the disabled or elderly individual cared for and so identifies emotionally with the individual cared for that they cannot separate themselves from the individual’s pain and suffering; in the balancing/boundary setting mode, the caregiver maintains a certain amount of distance from the individual cared for; and in the symbiotic mode, the caregiver gains from caring for the individual and does not wish for that responsibility to be taken from them. In terms of studies in Japan, Tsuchiya (2002) studied mothers of individuals with severe motor disabilities, she provided them with training to do what they could for their child, and she analyzed the attitudes of mothers who took on the task of assisting the child because of their guilt at having given birth to a child with a disability. In qualitative studies of mothers of children with SMID, Nakagawa (2003b; 2005) identified the mother’s sense of combining her identity with that of the child and trying to completely take on the child’s life and disability with a personal mission of mitigating the child’s disability; she termed this “total commitment” and identified the process of its origin and variation.

Nevertheless, such “perceptions of the caregiving role” are not considered within the cognitive model of stress and coping upon which many family care studies are based. Moreover, study results that do exist are few and far between. In addition, the impact that “perceptions of the caregiving role” has on burnout and mental and physical health of the caregiver has yet to be fully elucidated.

Thus, the current study had the following objectives. First, it sought to clarify the structure of “perceptions of the caregiving role” that mothers of children with SMID have. Second, it examined the impact that “perceptions of the caregiving role” have on the mothers’ well-being.

This study considered “perceptions of the caregiving role” in reference to the stress process model in caregiving settings (Pearlin et al. 1990) and clarified the impact of these perceptions on mothers’ well-being. Pearlin et al. (1990) denoted the level of disability and ADL as primary stressors and subsequent changes occurring in everyday life as secondary stressors; they grouped burnout, mental, and physical health into the final stress response and considered coping and social support as mediating factors in this process. In the
current study, "caregiving demand" was thus a primary stressor, changes occurring in everyday life due to care for a child with SMID were a "secondary stressor," the final outcome was "the mother's well-being," and "perceptions of the caregiving role" and "social support" were considered to mediate between the "primary stressor" and "secondary stressor" (Fig. 1). Additionally, "perceptions of the caregiving role" were assumed to affect "social support." This is because previous studies have suggested that the nature of perceptions a mother has about caring for a child affects her attitude toward seeking social support, such as accepting support from others or taking on that care alone without such support (Nakagawa 2003b).

![Analytical framework (hypothetical model)](image)

**Figure 1** Analytical framework (hypothetical model)

### II. Methods

1. **Target area**
   
   1) Demographics of the target area
   
   The target area for this study included cites in a metropolitan area with a population of 3.6 million (as of July 2006). In comparison to the rest of the country, the area is progressive in terms of its health and welfare services for children with SMID.

2) **Subjects and methods**
   
   Subjects for this study were mothers of children with SMID. Here, "children with SMID" are individuals who fulfill criteria for motor function of being "bedridden" or "able to sit up" as well as intellectual function indicated by "an IQ of 35 or below."

   Staff at 4 schools for the disabled (elementary, middle, and high school departments), 7 preschool habilitation facilities, and 3 medical facilities in the target area were asked to identify children meeting the above criteria for children with SMID and give their mothers a questionnaire that would later be collected by mail. Depending on circumstances when the questionnaire was given, some mothers of children who did not have SMID were also given the questionnaire. In addition, the questionnaire clearly indicated that answering was voluntary and that there would be no penalty for failure to answer, that it would be used only for research purposes, and that individual responses would not be disclosed. Privacy considerations were also clearly indicated and respondents were asked to respond anonymously. This survey was approved by the Research Ethics Committee of the Tokyo Metropolitan
University of Health Sciences (the first author’s institution). The survey was conducted from July to October 2004.

Four hundred and fifty-six copies of the questionnaire were distributed and 230 responses were received for a response rate of 50.4%. Responses had to be screened since, as stated previously, the questionnaire was also given to mothers of children who did not have SMID. To determine whether or not the child met the criteria for children with SMID, respondents were selected based on responses to the following survey items. That is, a negative response to the question about motor function of “Being bedridden” or “Able to sit up by himself/herself without leaning on something” as well as a negative response to the question about intellectual function of “Responds when his/her name is called” or “Can mimic simple things like ‘Bye-bye’” meant that the child was deemed to be a child with SMID, and its mother was a potential participant in this study. Responses from 66 mothers whose child did not meet these criteria, 5 mothers who failed to answer many of the questions, and 5 individuals who were not mothers were excluded, resulting in a total of 154 participants.

2. Measures

1) Dependent variable

The dependent variable in this study was the mother’s well-being, and indices of this well-being were mental burden, physical burden, and life satisfaction.

“Emotional exhaustion” was used as a scale to measure mental burden. “Emotional exhaustion” is a subscale of the “Family Care Maslach Burnout Inventory” (Nakatani 1992), which is a scale that was devised to measure burnout in a family caring for an elderly member. To some extent, it measures conditions when a respondent’s mental energy is drained and the respondent is emotionally exhausted. Use of existing mental health scales could lead to measurement of factors besides caregiving, so among burnout scales an “emotional exhaustion scale” more specifically tailored to care by family members was used. In addition, this scale was developed for use with families caring for an elderly member. To examine whether content suited a family caring for a child, the term “care” was replaced with “care for my child” and a preliminary study was conducted with 10 mothers of children with SMID. As a result, these respondents remarked that the content of 2 items “wasn’t exactly clear” or they failed to answer these items (“Since I care for my child, spending time with him/her is a chore” and “I do too much care for my child”), so the items were excluded and the scale consisted of the remaining 6 items. Responses to each item were on a 5-point scale from “Not at all” to “Definitely so” and were assigned a corresponding score from 0 to 4 points. Then, Cronbach’s alpha (α=.88) was calculated; once adequate values were obtained, the tallied score served as the “emotional exhaustion” score.

“Physical symptoms” served as a scale to measure physical burden. This scale is a checklist of physical symptoms that was devised by referring to the dimensions of “general fatigue” and “physical breakdown” from the “Cumulative Fatigue Symptoms Index (CFSI)” of Kosugo and Fujii (1987) and consists of 14 items such as “At times, I feel completely worn out” and “At times, I feel faint.” An answer of “Yes” to having a symptom was given a score of 1 point, and the tallied score served as the “physical symptoms” score.

Additionally, satisfaction with life overall was measured with the item “Overall, how satisfied are you with your life right now?” This item served to indicate “life satisfaction.”

2) Independent variables

(1) Primary stressor

Pearlin et al. (1990) defined direct causes of problems and difficulties in providing care, such as the mental and physical condition of the care recipient and caregiving demand, as primary stressors. In the current study, children cared for by participants were limited to children with SMID and the level of disability was consistent, so these aspects did not serve as variables. The following “caregiving demand” served as the primary stressor. “Caregiving demand” was devised by referring to the “Score for Seriously Handicapped Children Receiving Intensive Medical Care” of Suzuki et al.
This demand indicates the degree of medical management required; the higher the score, the greater the need for medical management and the greater the need for care. Respondents selected from 15 items such as “mechanical ventilation,” “tracheal intubation, tracheostomy,” and “nasopharyngeal airway tube” those that were “Required by my child,” and scores were assigned for each, such as “mechanical ventilation (10 points),” “tracheal intubation, tracheostomy (8 points),” and “nasopharyngeal airway tube (8 points).” The total points served as the “caregiving demand” score.

2. Secondary stressor level

Pearlin et al. (1990) described changes in everyday life such as family conflict, economic strains, and constriction of social and recreational life that were caused by primary stressors as secondary stressors. A preliminary study was conducted to devise survey items for secondary stressors as part of caring for a child with SMID. Participants were 9 mothers of children with SMID, which broke down into 3 mothers with preschool-age children, 3 with school-age children (with 1 child in an elementary school department, 1 in a middle school department, and 1 in a high school department), and 3 with children who had already graduated. Participants were asked to give open-ended responses with regard to problems in everyday life. Then, their responses were arranged and categorized, and 29 survey items were devised. Responses to each item were on a 4-point scale from “Not at all” to “A number of times” and were assigned a corresponding score from 0 to 3 points. In the current analysis, 2 items with numerous missing data ("My child can't be put in a facility (short-term)" and "My child requires somewhat specialized care, so he/she won't be accepted by a facility (school, day care or long-term facility, other)") were excluded. Cronbach's alpha was calculated (α=.901) for the remaining 27 items; once adequate values were obtained, the tallied rating score served as the "secondary stressor level."

3. Perceptions of the caregiving role

To devise items regarding “perceptions of the caregiving role,” content related to “perceptions of the caregiving role” was identified from semi-structured interviews and data from a previous study of 9 mothers of children with SMID on the “nature of your life up till now, including your experience as a mother” (Nakagawa 2003b) and from other studies. This content was arranged and categorized, and 15 items were subsequently devised. Responses to each item were on a 4-point scale from “I strongly disagree” to “I completely agree” and were assigned a corresponding score from 0 to 3 points. The content of the 15 items is, along with the results of confirmatory factor analysis as described later, shown in Table 1.

4. Social support

In a total of 8 items, respondents were asked about what forms of social support they received. Four of those items indicated emotional support, i.e. “Someone listens to my concerns and worries,” “Someone encourages me,” “Someone helps me to relax," and “Someone looks out for and cares for me.” The remaining 4 items indicated instrumental support, i.e. “Someone who will look after my child for 2-3 hours,” “Someone who will look after my child from about 9 in the morning to 6 at night,” "Someone who will look after my child for 3-4 days,” and “Someone I can ask to go shopping or run errands.” At the same time, respondents were asked who provided that support. Support providers were grouped into 5 types, i.e. “spouse,” “a fellow family member other than one’s spouse,” “relatives living elsewhere,” “a friend, acquaintance, or neighbor,” or “an expert, service organization or facility, helper, nurse, etc.” If the 5 support providers provided 1 of the 8 forms of social support, a score of 1 was given. If no such support provider provided that support, a score of 0 was given. This constituted a scale for each of the 5 support providers, and Cronbach’s alpha was calculated for each (spouse: α=.819, a fellow family member other than one’s spouse: α=.849, relatives living elsewhere: α=.849, a friend, acquaintance, or neighbor: α=.725, an expert or service organization: α=.786). Once generally acceptable values were reached, these were tallied by support provider. The total score was calculated and served as the “support of one’s spouse,” “support of fellow family members,” “support of relatives living elsewhere,” “support of a friend, acquaintance, or neighbor,” and “support of an expert or service organization” score.

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Control variables
All of the respondents were mothers, so sex and familial relationship were excluded, and household income and age were entered as control variables. Regarding household income, respondents were asked "the total income for the previous year (including tax) of all immediate family members." Responses ranged from "no income" to "under 1 million yen," "1-1.99 million yen," "2-3.99 million yen," "4-5.99 million yen," "6-7.99 million yen," "8-9.99 million yen," "10-11.99 million yen," "12-13.99 million yen," "14-15.99 million yen," and "16 million yen or more" and were assigned a corresponding score from 1 to 11 points. Actual age was used for age.

Table 1 Structure of "perceptions of the caregiving role" (N=154)

<table>
<thead>
<tr>
<th>Factor 1 “Being solely responsible for the role”</th>
<th>Factor loadings&lt;sup&gt;a) &lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’d be worried about entrusting my child to anyone else but me</td>
<td>.828</td>
</tr>
<tr>
<td>I’m the only one who can care for my child</td>
<td>.806</td>
</tr>
<tr>
<td>I’m hesitant about institutionalizing my child</td>
<td>.706</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor 2 “Primacy of the caregiving role”</th>
<th>Factor loadings&lt;sup&gt;a) &lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>I try to devote myself to my child</td>
<td>.808</td>
</tr>
<tr>
<td>I don’t feel like I’ve been given an unmanageable burden</td>
<td>.529</td>
</tr>
<tr>
<td>I have to think about not just what makes my child happy</td>
<td>.502</td>
</tr>
<tr>
<td>but what also makes me happy</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor 3 “Maximization of role involvement”</th>
<th>Factor loadings&lt;sup&gt;a) &lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>I try to do whatever I can for my child</td>
<td>.989</td>
</tr>
<tr>
<td>I try to do everything I can to minimize my child’s disability</td>
<td>.384</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor 4 “Recognition of personal gain”</th>
<th>Factor loadings&lt;sup&gt;a) &lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Because of my child, I know things now that I hadn’t known before</td>
<td>.852</td>
</tr>
<tr>
<td>I’ve had a variety of experiences because I had a child</td>
<td>.821</td>
</tr>
<tr>
<td>I’ve been able to grow personally because of my child</td>
<td>.722</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor 5 “Role captivity”</th>
<th>Factor loadings&lt;sup&gt;a) &lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>There’s unspoken pressure from people around me to try my best to care for my child</td>
<td>.891</td>
</tr>
<tr>
<td>I suffer disdain from people around me if I try to distance myself, even a little, from my child</td>
<td>.658</td>
</tr>
</tbody>
</table>

a) Figures represent standardized values
b) Reverse items

|\( \chi^2 \)=78.843, df=60, p=.052, GFI=.930, AGFI=.894, CFI=.969, RMSEA=.045 |

III. Analysis

In the first stage, factors for “perceptions of the caregiving role” were identified with exploratory factor analysis and examined with confirmatory factor analysis.

In the second stage, the primary stressor was “caregiving demand,” changes in everyday life caused by the primary stressor were a “secondary stressor,” the final outcome was “the mother’s well-being,” and “perceptions of the caregiving role” and “social support” mediated the primary stressor and secondary stressor. "Perceptions of the caregiving role" were assumed to affect "social support," and Structural Equation Modeling (SEM) was done using maximum likelihood estimation based on a hypothetical model (Fig. 1) with the mother’s age and household income as control variables. In Fig. 1, the components of “perceptions of the caregiving role” and “social support” are not shown for simplification, but in actual modeling all of the paths between each variable comprising these components were drawn. That is, factors for “perceptions of care” that were identified in the first stage were considered,
and "support of one's spouse," "support of fellow family members," "support of relatives living elsewhere," "support of a friend, acquaintance, or neighbor," and "support of an expert or service organization" were considered for "social support." Paths between each of these and between other variables were drawn in the actual hypothetical model. In addition, covariances between control variables were assumed. SPSS ver.13.0, Amos ver.5.0 was used for the above analysis.

IV. Results

1. Respondent demographics

In terms of their relationship to the child, all of the respondents were the mother of the child. Average age was 39.8 years (SD=7.1) and the child had been cared for an average of 9.5 years (SD=6.6). The mother's highest level of education was middle school for 1.9% of respondents, high school for 33.8%, vocational school for 16.9%, junior or technical college for 29.2%, university for 15.6%, and graduate school for 1.9%. Household income for the previous year was 0 yen for 2.6% of respondents, under 1 million yen for 0.6%, 1-1.99 million yen for 1.3%, 2-3.99 million yen for 12.3%, 4-5.99 million yen for 29.9%, 6-7.99 million yen for 22.7%, 8.0-9.99 million yen for 13.6%, 10-11.99 million yen for 8.4%, 12-13.99 million yen for 3.2%, 14-15.99 million yen for 0.6%, and 16 million yen or more for 4.5%. In terms of employment status, 10.4% of respondents were employed (including full-time and part-time) and 89.6% were not.

All of the children had a certificate for the physically disabled, with 94.8% having a Class 1 disability and 5.2% having a Class 2 disability; 15.6% of children did not have a certificate for the mentally disabled while 84.4% did, with that mental disability corresponding to an IQ of 20 or below for 98.5% and an IQ of 21 to 35 for 1.5%. The average age of the child was 9.8 years (SD=6.6); in terms of facility or school placement, 31.8% of children were in a kindergarten, nursery, or preschool daycare facility, 27.9% attended an elementary school or elementary school department of a school for the disabled, 3.9% received the same education through home visits, 14.3% attended a middle school or middle school department of a school for the disabled, 1.9% received the same education through home visits, 9.7% attended a high school or high school department of a school for the disabled, and 5.8% were in a day care facility or local workshop. In addition, 71.4% of children required daily medical care while 28.6% did not, with that medical care (for those requiring care) breaking down into home mechanical ventilation for 7.3%, tracheostomy care for 18.2%, care for a nasopharyngeal airway tube for 9.1%, oxygen inhalation for 10.0%, suction for 56.0%, persistent inhalation 9.1%, nasogastric tube feeding (as well as that via a gastrostomy tube) for 100%, and regular self-catheterization for 1.8%.

2. Structure of "perceptions of the caregiving role"

First, exploratory factor analysis of the 15 items was done using the principal factor method (Promax rotation), and 5 factors were identified on the basis of an eigenvalue of 1 or larger. One item that did not have sufficient factor loading ("I can't help it if I have to sacrifice myself for my child") was excluded from analysis, exploratory factor analysis of the remaining 14 items was done again using the principal factor method (Promax rotation) assuming 5 factors. One item that again did not have sufficient factor loading ("The role of caring for my child is naturally one I should fulfill") was excluded, and exploratory factor analysis of the remaining 13 items was done again using the principal factor method (Promax rotation) assuming 5 factors.

Next, reverse items were dealt with and then confirmatory factor analysis was done using Amos in order to verify the results of exploratory factor analysis. Analysis was done with a model assuming that corresponding items were affected by the 5 factors and that there were covariances between all of the factors. Goodness of fit indices were \( \chi^2 \text{=75.737, df=55, } p\leq0.05, \text{ GFI=.933, AGFI=.889, CFI=.966, RMSEA=.050, and AIC=147.737.} \) Factor interpretation and naming was as follows. Factor 1 is "being solely responsible for the role" in which the caregiver tries to take on the caregiving role and not entrust it to others. Factor 2 is "primacy of the caregiving role" in which the
caregiver places a higher priority on the caregiving role rather than on his or her self or other matters. Factor 3 is “maximization of role involvement” in which the caregiver maximizes his or her involvement in the caregiving role. Factor 4 is “recognition of personal gain” in which the caregiver recognizes that he or she has gained something from taking on the caregiving role. Factor 5 is “role captivity” in which the caregiver succumbs to normative pressure regarding fulfillment of the caregiving role. In addition, inter-factor correlations between “being solely responsible for the role” and “recognition of personal gain,” “being solely responsible for the role” and “role captivity,” “primacy of the caregiving role” and “recognition of personal gain,” “primacy of the caregiving role” and “role captivity,” and “maximization of role involvement” and “role captivity” were not significant, so analysis was done again in the model with inter-factor correlations of 0.

Goodness of fit indices were $\chi^2=78.843$, df=60, p=.052, GFI=930, AGFI=.949, CFI=.969, RMSEA=.045, and AIC=140.843 and provided results that better fit the data than the initial model did. Analytical results from the final model are shown in Table 1.

3. Factors associated with well-being

Next, “being solely responsible for the role,” “primacy of the caregiving role,” “maximization of role involvement,” “recognition of personal gain,” and “role captivity” were considered as part of “perceptions of the caregiving role” in the hypothetical model. SEM was done, and goodness of fit indices were $\chi^2=363.957$, df=192, p<.001, GFI=.849, AGFI=.745, CFI=.829, and RMSEA=.077. Thus, modeling was done while eliminating non-significant paths one by one and while also eliminating variables that consequently had no paths entering or leaving. In addition, both paths in the direction hypothesized and in the opposite direction were examined while taking the goodness of fit indices into account. Based on modification indices, furthermore, covariances between error variances were added within the limits of theoretical understanding. The final model that resulted is shown in Fig. 2. Goodness of fit indices were $\chi^2=179.184$, df=154, p=.081, GFI=.901, AGFI=.865, CFI=.969, and RMSEA=.033. Significant paths are indicated below.

1) Association between primary stressor and secondary stressor levels and well-being

“Caregiving demand,” a primary stressor, was not significantly associated with the “secondary stressor level,” “perceptions of the caregiving role,” or “social support.” Independent of these, a higher level of “caregiving demand” was directly associated with increased “physical symptoms” (.19, p<.01).

A higher “secondary stressor level” was associated with less “life satisfaction” (-.46, p<.001), increased “emotional exhaustion” (.64, p<.001), and increased “physical symptoms” (.32, p<.001).

2) Association between “perceptions of the caregiving role” and well-being

Of the 5 “perceptions of the caregiving role” presented in the hypothetical model, 3 were significantly associated with well-being: “being solely responsible for the role,” “recognition of personal gain,” and “role captivity.” Of these, “role captivity” had the greatest effect on well-being (Table 2).

Greater “role captivity” was associated with the indirect diminishing of well-being via the following multiple paths (Here, the standardized coefficient and level of significance are indicated in parentheses). Greater “role captivity” was associated with a higher “secondary stressor level” (.39, p<.001) and with diminished well-being through enhancement of this “secondary stressor level.” In addition, greater “role captivity” was associated with less overall social support by each support provider (“support of one’s spouse,” -.33, p<.001; “support of fellow family members,” -.20, p<.05, “support of relatives living elsewhere,” -.19, p<.05; “support of a friend, acquaintance, or neighbor,” -.34, p<.001; and “support of an expert or service organization,” -.18, p<.05). Greater “role captivity” was associated with enhancement of the “secondary stressor level” through limiting of the “support of one’s spouse” and subsequently diminished well-being or greater “role captivity” was associated with diminished “life satisfaction” through limiting of the “support of one’s spouse.” Furthermore, greater “role captivity” was associated with less “recognition of personal gain”
Figure 2 Final model
<table>
<thead>
<tr>
<th>Independent variables (Coefficients of determination)</th>
<th>Being solely responsible for the role</th>
<th>Recognition of personal gain</th>
<th>Role of one's spouse</th>
<th>Household income</th>
<th>Age</th>
<th>Caregiving demand</th>
<th>Secondary stressor level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional exhaustion (R²=.415)</td>
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<td>.000</td>
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<td>.000</td>
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<tr>
<td>Direct effect</td>
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<td>.030</td>
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<td>.644</td>
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<td>Total effect</td>
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<td>.030</td>
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<td>Physical symptoms (R²=.179)</td>
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<td>Direct effect</td>
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a) Independent variables that had no effect on the 3 variables associated with well-being were omitted.
b) Figures represent standardized values.
(-.40, p<.001) and was associated with diminished “life satisfaction” through a reduction in the “recognition of personal gain.” The indirect effect that greater “role captivity” had on well-being via the paths above was .290 for “emotional exhaustion,” .145 for “physical symptoms,” and -.355 for “life satisfaction” (Table 2). The total effect of “role captivity” on well-being was the greatest among the “perceptions of the caregiving role;” it had a relatively substantial effect, second only to the “secondary stressor level,” even in comparison to other variables (Table 2). In addition, all of the effects that “role captivity” had on well-being were indirect (Table 2).

A greater feeling of “being solely responsible for the role” was directly associated with less “life satisfaction” (-.15, p<.05). In addition, this greater feeling of “being solely responsible for the role” was associated with an increased “secondary stressor level” (.18, p<.05) and with diminished well-being through the enhancement of this “secondary stressor level.” In addition, greater feeling of “being solely responsible for the role” was associated with less of 2 types of social support, i.e. “support of a friend, acquaintance, or neighbor” (.26, p<.01) and “support of an expert or service organization” (.33, p<.001).

Greater “recognition of personal gain” was directly associated with greater “life satisfaction” (.22, p<.001).

3) Association between social support and well-being

Of the forms of social support by the support provider, only “support of one’s spouse” was significantly associated with well-being; “support of one’s spouse” was associated with greater “life satisfaction” (.19, p<.01). Greater “support of one’s spouse” was also associated with a lower “secondary stressor level” (-.19, p<.05) and was indirectly associated with enhanced well-being through lowering of this “secondary stressor level.”

4) Association between demographic characteristics and well-being

In terms of demographic characteristics, higher “household income” was associated with greater “support of one’s spouse” (.25, p<.01) and was associated with enhanced “life satisfaction” and with lowering of the “secondary stressor level” through greater “support of one’s spouse.” Furthermore, higher “household income” was indirectly associated with enhanced well-being through lowering of this “secondary stressor level.”

In addition, increased “age” was associated with a lower level of “role captivity” (-.30, p<.001). That is, the greater one’s age, the less one experienced “role captivity.” Increased “age” was associated with lowering of the “secondary stressor level” through lessening of this “role captivity,” further enhancing well-being. That said, increased “age” was associated with less “support of one’s spouse” (-.31, p<.001) and “support of relatives living elsewhere” (-.32, p<.001) and was indirectly associated with less well-being through limiting of the “support of one’s spouse.” In terms of its total effect, however, increased “age” was associated with greater well-being (Table 2), and the greater one’s age the greater one’s well-being.

V. Discussion

The objectives of this study were to clarify the structure of “perceptions of the caregiving role” of mothers of children with SMID and to clarify the impact of these “perceptions of the caregiving role” on the mothers’ well-being.

Five factors regarding “perceptions of the caregiving role” were identified: “being solely responsible for the role,” “primacy of the caregiving role,” “maximization of role involvement,” “recognition of personal gain,” and “role captivity.” Of these, “being solely responsible for the role,” “primacy of the caregiving role,” and “maximization of role involvement” coincided with, as indicated in previous studies, the attitudes and perceptions that mothers of a child with a disability or chronic illness had regarding the role of caring for a child.

In addition, this study identified these mothers’ sense of being constrained by normative pressure regarding fulfillment of the caregiving role as “role captivity,” and this may correspond to the “role captivity” described by Pearlin (1983;1989) and Aneshensel
et al. (1993). Those authors described “role captivity” as circumstances forcing a person to take on an involuntary social role, and they cited the involuntariness of the role as one of its features. Mothers of children with SMID in the current study recognized normative pressure to fulfill the caregiving role but did not go so far as to express the involuntariness of the role, so in this regard there is a disparity between this study and previous studies. However, this disparity may be due to variations in the origin of “role captivity” resulting from the relationship between the caregiver and the individual cared for or resulting from cultural traits of the US and Japan, so this point is a topic for future study. That is, studies by Pearlin (1983;1989) and Aneshensel et al. (1993) were of families caring for an elderly member and the relationship between the caregiver and the individual cared for was one spouse caring for another or an adult child caring for a parent, while the current study was of mothers and children, so the caregiving role may have been more readily accepted. On the other hand, there are cultural traits such as the level of self-acceptance of negative emotions in regard to devotion to the family or the extent to which negative emotions can be openly disclosed; these traits conceivably affected the extent to which the involuntariness of the caregiving role was expressed. In terms of studies in Japan, Minamiyama (2006) examined the mother as the caregiver, like the current study did, in a study of family care for the mentally ill. He indicated that mothers of the mentally ill display “role captivity” characterized by the involuntariness of the role, which he (2006:82-83) interpreted as follows: “Even if a mental illness occurs once the individual is independent of the parent or if the parent is elderly, the parent remains in a position to care for the individual and thus easily succumbs to ‘role captivity.’” In comparison, characteristic of the perceptions of mothers, which were the participants in the current study, were the perception that they are partly to blame for causing their child’s disability and their sense of self-blame regarding the disability, as were related in interviews beforehand. This perception about the cause of the disability and sense of self-blame may increase the degree of acceptance of the caregiving role and thus reduce the involuntariness of the caregiving role. As mentioned earlier, comparison of care for the elderly in the US, care for the mentally ill in Japan, and care for children with SMID in Japan suggests that the degree of acceptance of the caregiving role is involved in the origination of “role captivity” and that factors like the relationship between the caregiver and the individual cared for, age of the individual cared for, perception about the cause of the disability, and cultural traits may represent ones that affect the degree of acceptance of the caregiving role. A likely topic for the future may be the multifaceted and systematic study of the context in which “role captivity” originates, how it manifests, and the effects its origination has.

In addition, “role captivity” also attracted attention because of the extent of its impact on well-being. And yet characteristic of this strain is the limiting of social support overall, resulting in an indirect effect on well-being through enhancement of the secondary stressor level.

“Being solely responsible for the role” had the ability to limit “support of a friend, acquaintance, or neighbor” and “support of an expert or service organization.” While the limiting ability of “role captivity” reached all forms of support, “being solely responsible for the role” was characteristic in that it only acted on external support. Furthermore, “being solely responsible for the role” also had a directly negative effect on “life satisfaction.” The belief mothers thrust upon themselves of “I’m the only one who can care for my child” may linked to less satisfaction with life overall.

“Recognition of personal gain” was associated with greater “life satisfaction.” “Recognition of personal gain” has been studied as one aspect of the positive perceptions of care. A previous study in Japan has indicated that the positive perceptions of care of a family with an elderly member are significantly associated with that individual’s desire to live (Yamamoto et al. 2002). Similarly, results of the current study suggest that “recognition of personal gain” may be linked to satisfaction with life overall, and this finding coincides with results of previous studies. There is, however, the possibility of similarities, i.e. any positive emotion may thus have a significant association, so attention to
methodology is probably needed in the future to further clarify this aspect's impact on perceptions of care.

In addition, this study resulted in the following recommendations for its practical application. To start with, "role captivity" has a major impact on the mother's well-being, and younger mothers in particular experience greater role captivity, so practical considerations are needed. In the initial stages when a child manifests a disability, the mother is sensitive to outside appraisals of her and her child. As part of this, the mother senses normative pressure and her own perceptions are constrained. In addition, numerous experts are extensively involved while the child is very young; a previous study (Nakagawa, 2003b) has indicated that the mother senses normative pressure from the language and behavior of experts in health, medical care, welfare, and habilitation as well, so caution is required in this regard.

Conversely, "recognition of personal gain" enhances life satisfaction, so its incorporation in support techniques should have an effect, but close attention should be paid to see that a lack of actual support is not masked by the mother's belief in "the benefits of care." Similarly, the current results indicate that support of an expert or service organization is not linked to lessening of secondary stressors and enhancement of well-being for the mother. Aspects of how support has failed to be effective must be studied.

A topic for the future is the need to organize concepts regarding beliefs about care. Numerous concepts such as "coping," "cognitive appraisal of care," and "perceptions of the caregiving role" have thus far been identified. "Coping" refers to "cognitive and behavioral efforts to reduce and minimize stress (Lazarus & Folkman 1984)" and thus is expressed as an individual's attempts at overcoming stressful situations. In addition, "cognitive appraisal of care" emphasizes an "appraisal" of care. Thus, such concepts differ in their individual meaning and emphasis but in reality they overlap when identified by analysis. In the future, these concepts need to be organized.

In addition, this study is based on analysis of data from study participants residing in an area with advanced health and welfare services. In the future, similar studies must be conducted in areas without such advanced services and in regions presumed to have greater normative pressure.

Addendum This study summarizes part of the research conducted under a Grant-in-Aid for Scientific Research from the Japan Society for the Promotion of Science of the Ministry of Education, Culture, Sports, Science and Technology (Basic Research (c) (2 Project No. 13837016).

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Note
1) Items for secondary stressors are as follows. Asterisked items (*) were excluded from analysis.
   ① No personal time ② Inability to think about going out ③ Interference with household chores, shopping, one's career, and other vital errands ④ Limited contact with friends and acquaintances ⑤ Lack of information provided by doctors and nurses ⑥ Difficulty in communicating with doctors and nurses ⑦ Uncertainty about how to care for one's child ⑧ Each aspect of care is arduous and difficult ⑨ A hospital that can fully examine one's child is not located nearby ⑩ The child's condition is unstable ⑪ Numerous uncertainties about the future for one's child, one's self, and one's family ⑫ Trouble with accommodations unsuited to caring for one's child ⑬ Difficulty using a stroller, wheelchair, clothing, car, etc. ⑭ Financial burden ⑮ One's child cannot receive adequate habilitation, rehabilitation, education, or treatment ⑯ Difficulty obtaining information about welfare and medical care ⑰ Physically draining, lack of energy ⑱ Lack of sleep ⑲ Contacting relevant organizations is difficult ⑳ Taking one's child to a relevant organization is difficult ⑴ Difficulty putting one's child in a facility (short-term) ⑵ Lack of anyone at home to look after one's child ⑶ One's child requires somewhat specialized care, so no facility will accept him/her ⑷ Considerable worry about the child's disability ⑸ Inability to adequately tend to other family members (young sibling/other) ⑹ Inability to participate in events of other family members (young sibling/other) ⑺ Poor relationship with one's spouse ⑻ Inability to go on family outings ⑼ Poor relationship with relatives

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References


