FACTORS PREDICTING CAREGIVING BURDEN AMONG OLDER CAREGIVERS OF STROKE SURVIVORS IN THE COMMUNITY

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ABSTRACT

BACKGROUND: The number of older caregivers of stroke survivors is rising. However, the knowledge of factors influencing caregiving burden of older caregivers is limited. The Caregiving Stress Process and related literature were adapted to investigate the predictors of caregiving burden.

PURPOSE: To describe caregiving burden and to investigate predicting factors of caregiving burden among older caregivers.

METHODS: The sample was recruited using convenience sampling and consisted of 160 caregivers aged 60 years and over who had provided care for stroke survivors for at least one month. Predicting factors were analyzed by ordinal logistic regression. Instruments included Chula ADL Index, Chula Mental Test, revised Thai Rosenberg Self-Esteem Scale, revised Jalowiec Coping Scale, revised Thai Multi-Dimensional Scale of Perceived Social Support, and Thai Burden Interview.

RESULT: Most older caregivers had little or no caregiving burden. Stroke survivors’ physical function (OR=0.75, p=0.001, 95% confidence interval (CI): 0.64-0.89) and older caregivers’ self-esteem (OR=0.84, p=0.002, 95% confidence interval (CI): 0.75-0.94) predicted caregiving burden.

CONCLUSION: Caregiving burden decreases when stroke survivors have high physical function and older caregivers have high self-esteem. The findings can be used to create rehabilitation programs for stroke survivors and older caregivers.

Keywords: Older caregivers, Caregiving burden, Physical function, Self-esteem, Stroke survivors

I. INTRODUCTIONS

More than ever before, older persons become primary caregivers for their spouses and children between 2015 and 2020 (National Alliance for Caregiving and AARP Public Policy Institute.2020). Due to an aging society and smaller family size caused by adults’ relocation for jobs, older caregivers live without adult family members (Prasartkul et al., 2013). Moreover, with longevity of stroke survivors (Butsing, Mawn, Suwannapong, & Tipayamongkolgul, 2018), adult caregivers become older caregivers (Watanabe et al., 2015). Older caregivers provide assistance in physical, emotional, and social support for stroke survivors which, despite seeming easy for younger caregivers, are difficult for older caregivers who experience age-related physical and cognitive function decline and have chronic diseases (Longphasuk, Monkong, & Sirapongam, 2018). Therefore, they lack physical strength and are limited in performing caregiving tasks (Muñoz-Bermejo, Villafaina, Collado-Mateo, Postigo-Mota, & Adsuar, 2019), resulting in high caregiving burden which refers to personal perception of suffering emotionally, physically, socially, and financially (Zarit, Todd, & Zarit, 1986). It can last until five years of
caregiving experience (Jaracz et al., 2015). Older caregivers perceived greater caregiving burden than younger caregivers (Koumoutzis, Cichy, Dellmann-Jenkins, & Blankemeyer, 2020), and mentioned higher caregiving burden with greater frailty (Alves, Flesch, Cachioni, Neri, & Batistoni, 2018) and higher intention to institutionalize stroke survivors (Vandepitte et al., 2018). Although previous studies showed that adult caregivers had caregiving burden due to physical function of stroke survivors, hours of care, and social support (Boonsin, Deenan, & Wacharasin, 2021; Han et al., 2017), there is little authentic knowledge about this phenomenon in older caregivers. Therefore, this study aimed to describe caregiving burden and examine predictive ability of stroke survivors’ factor (physical function) and older caregivers’ factors (physical function, cognitive function, self-esteem, effective coping, and social support) in explaining the caregiving burden of older caregivers of stroke survivors.

II. LITERATURE REVIEW

Caregiving Stress Process (Pearlin, Mullan, Semple, & Skaff, 1990) and literature reviews of aging changes were used to guide the conceptual framework. Caregiving burden, as an outcome of caregiving process, (Boonsin et al., 2021) is the result of an interaction among background and context, primary stressors, secondary stressors, and mediators (Pearlin et al., 1990). Higher impairment of physical function of stroke survivors as primary stressor led to higher caregiving demands, which directly increased caregiving burden (Kunyodying, Pothiban, & Khampolsiri, 2015). Furthermore, aging changes of caregivers reduced their physical function and cognitive function considered as primary stressors that were personal stressors causing reduced ability to perform activities of daily living (ADLs) and barriers to the management of caregiving tasks by themselves (Muñoz-Bermejo et al., 2019), resulting in high caregiving burden. Secondary stressors caused by severity of primary stressors led to role strain and intrapsychic strains when caregivers interpreted caregiving task as a difficulty inhibiting the development of caregivers’ self-esteem (Pearlin et al., 1990). These interplays contribute to caregiving burden. Despite difficulty in performing caregiving and other roles, if older caregivers had high effective coping (Barusch & Spaid, 1989) and sufficient social support (Kunyodying et al., 2015) as two important mediators, caregiving burden would decrease.

III. METHODOLOGY

This research was conducted in older caregivers providing care for stroke survivors in community. Participants were 160 primary older caregivers of stroke survivors living in nine sub-districts in Saraburi province, Thailand. Three districts with the highest numbers of stroke survivors were selected from 13 districts of the province. Three sub-districts with the highest numbers of stroke survivors were selected from each selected district. Finally, a convenience sample of older caregivers who were 60 years old and over, and had provided care for at least one month was identified from stroke survivors’ registration in each sub-district. Sample size was calculated using power analysis, and the estimated population effect size (γ) of multiple regression was determined using the small value of $R^2 = 0.09$ (Polit & Beck, 2008).

Most of the older caregivers were female with a mean age of 67.61 years, Buddhist, and married. Almost all of them (96.87%) lived with family and had at least one chronic disease (43.13%). Older caregivers provided care for stroke survivors who were male (71.90%) with a mean age of 67.82 years, Buddhist (98.80%), married (79.40%), and unemployed (77.50%), as well as had physical disabilities (67.50%), and communication deficits (14.40%).

Data Collection

The processes agreed with ethics principles for human research with approval from the Research Ethics Committee of the Faculty of Nursing, Chiang Mai University. Participants were informed of their rights. Data collection was conducted between April and October 2018. The researcher read questions without explanation. Questionnaires were administered based on ease of use, and participants took a 10-minute break. Older caregivers answered by themselves to complete the instruments within 60-100 minutes and were proxy respondents for stroke survivors.

The demographic data form was used to obtain characteristics of older caregivers and stroke survivors. The Chula ADL Index was used to assess physical function of older caregivers and stroke survivors regarding complexity of ADLs (Sutthichai Jitapunkul, Kamolratanakul, & Ebrahim, 1994). Cronbach’s alpha tested with older caregivers and stroke survivors were 0.76 and 0.83, respectively. The Chula Mental Test was used to assess cognitive function (Sutthichai Jitapunkul, Lailert, Worakul, Srikiatkhachorn, & Ebrahim, 1996). Cronbach’s alpha was
0.77. The revised Thai Rosenberg Self-Esteem Scale was used to assess self-esteem (Wongpakaran & Wongpakaran, 2012). Cronbach’s alpha was 0.81. The revised Jalowiec Coping Scale translated into Thai by the researcher was used to assess effective coping (Jalowiec, 2003). Cronbach’s alpha was 0.96. The revised Thai Multi-Dimensional Scale of Perceived Social Support was used to assess social support (Wongpakaran & Wongpakaran, 2012). Cronbach’s alpha was 0.86. The Thai Burden Interview was used to assess caregiving burden, including personal strain, privacy conflict, guilt, and uncertain attitude. Scores are interpreted into 0-20 (little or no burden), 21-40 (mild to moderate burden), 41-60 (moderate to severe burden), and 61-88 (severe burden). Cronbach’s alpha was 0.90

### Data Analysis

Data were analyzed with descriptive and inferential statistics. Predicting factors were analyzed using ordinal logistic regression.

## IV. RESULTS

Older caregivers spent an average of 4.60 hours/day on caregiving, with a mean caregiving duration of 4.98 years. Caregiving tasks most frequently performed were ADLs assistance such as bathing (33.75%), instrumental activities of daily living (IADLs) assistance such as cooking (80.60%) and housework (57.10%), and medical assistance such as follow up management (39.40%) and medical management (25.00%).

This study reveals that 60.60% of the stroke survivors had low physical function while 53.80% of older caregivers had moderate physical function. Additionally, older caregivers had high self-esteem (90.60%) and normal cognitive function (97.50%), but 99.40% of them had low effective coping and moderate social support (42.50%).

Table 1 shows that older caregivers had little or no caregiving burden (76.30%). When considering subdomain, guilt was reported in greater percentage of mild to moderate (30.60%), moderate to severe (13.10%), and severe (5.00%) than other subdomains.

### Table 1: Caregiving Burden Score of Older Caregivers (n = 160).

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>(\bar{x}) (SD)</th>
<th>Little or no n(%)</th>
<th>Mild to moderate n(%)</th>
<th>Moderate to severe n(%)</th>
<th>Severe n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal strain</td>
<td>5.69(6.74)</td>
<td>112(70.00)</td>
<td>37(23.10)</td>
<td>8(5.00)</td>
<td>3(1.90)</td>
</tr>
<tr>
<td>Privacy conflict</td>
<td>0.99(2.33)</td>
<td>142(88.80)</td>
<td>12(7.50)</td>
<td>4(2.50)</td>
<td>2(1.30)</td>
</tr>
<tr>
<td>Guilt</td>
<td>5.34(4.39)</td>
<td>82(51.30)</td>
<td>49(30.60)</td>
<td>21(13.10)</td>
<td>8(5.00)</td>
</tr>
<tr>
<td>Uncertain attitude</td>
<td>2.05(2.10)</td>
<td>122(76.30)</td>
<td>36(22.50)</td>
<td>2(1.30)</td>
<td>-</td>
</tr>
<tr>
<td>Total scores</td>
<td>14.08(12.17)</td>
<td>122(76.30)</td>
<td>30(18.80)</td>
<td>8(5.00)</td>
<td>-</td>
</tr>
</tbody>
</table>

Factors influencing caregiving burden were stroke survivors’ physical function and older caregivers’ self-esteem shown in Table 2. An increase in physical function impairment of stroke survivors was associated with an increase in the odds of caregiving burden to a high level, with odd ratio of 0.75 (p=0.001) when controlling other variables. An increase in self-esteem of older caregivers was associated with a decrease in the odds of caregiving burden to a low level, with odd ratio of 0.84 (p=0.002) when controlling other variables. For model fit and the goodness-of-fit, both independent variables could predict caregiving burden and the parallel line met the assumption (p=0.29). The model fit test showed -2 Log Likelihood (-2LL) between intercept (214.53) and final value (179.30), and Chi-Square = 35. 24, df = 6, p<0.01. The goodness-of-fit showed no significant difference between expected frequency and observation frequency (p>0.05).

### Table 2: Predictors of Caregiving Burden.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Estimate</th>
<th>Std. Error</th>
<th>Wald test</th>
<th>odds ratios (exp_B)</th>
<th>Sig.</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lower Bound Upper Bound</td>
</tr>
<tr>
<td>Caregiving burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little or none</td>
<td>-5.51</td>
<td>3.76</td>
<td>2.15</td>
<td>0.004</td>
<td>0.14</td>
<td>0.00 6.35</td>
</tr>
<tr>
<td>Mild to moderate</td>
<td>-3.42</td>
<td>3.75</td>
<td>0.83</td>
<td>0.03</td>
<td>0.36</td>
<td>0.00 50.39</td>
</tr>
<tr>
<td>Stroke survivors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Physical function</td>
<td>-0.28</td>
<td>0.08</td>
<td>11.66</td>
<td>0.75</td>
<td>0.001</td>
<td>0.64 0.89</td>
</tr>
<tr>
<td>Older caregivers</td>
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</table>
Overall, most older caregivers had little or no total caregiving burden and subdomains. That is, they considered caregiving as unlikely to interfere with their privacy, allowing them to maintain social participation and manage their life while caring for stroke caregivers. However, focusing on each subdomain, most older caregivers perceived guilt to be more severe than others. One explanation is that they could not provide care as well as expected, possibly due to age-related decline in their physical ability (Muñoz-Bermejo et al., 2019). Personal strain was perceived as the second most severe subdomain because caregiving triggered psychological problem. Moreover, many caregiving tasks required longer time from older caregivers, causing privacy conflicts. Uncertain attitude was the least perceived subdomain. This contradicted previous findings that privacy conflict was perceived by most adult caregivers in Thailand (Fumaneesheat & Ingviya, 2020) and personal strain was reported by most Singaporean adult caregivers (Tan, Williams, Tan, Clark, & Morris, 2020).

Physical function of stroke survivors and self-esteem of older caregivers could predict caregiving burden. In this study, older caregivers had to assist in many tasks in long-term care for stroke survivors that took too much time to complete due to stroke survivors’ low physical function. Consistently, older caregivers experienced more caregiving burden when stroke survivors had low physical function (Kunyodying et al., 2015). For self-esteem, older caregivers expressed high self-esteem because they felt self-worth and pride for being able to perform caregiver roles (Pearlin et al., 1990) despite health problems and moderate physical function. Caregivers with low self-esteem reported high caregiving burden (Pudelewicz, Talarska, & Báczyk, 2019).

However, good physical function, cognitive function, social support, and effective coping of older caregivers could not reduce caregiving burden. Possible explanation is that the majority of older caregivers in this study were in early stage of physical function decline. Therefore, they ignore minor physical limitations and focus more on caring for stroke survivors. Moreover, they had good cognitive function. It may affect caregiving burden only in older caregivers with poor cognitive function (Pertl, Lawlor, Robertson, Walsh, & Brennan, 2015). In Thai society, caregivers are too considerate to ask others for support, and choose to perform caregiving tasks by themselves (Pasri, Isaramalai, & Hattakit, 2015), implying that they would seek support only when confronting problems. Social support in problematic situations does not reduce caregiving burden whereas daily social support can reduce caregiving burden (Kruithof et al., 2016). The finding contradicted another study where social support could decrease caregiving burden (Kunyodying et al., 2015). In Buddhist philosophy, Thai people remain humble notwithstanding success in life (Wichittaphan, 2018). Thus, they did not manifest themselves as being able to cope with problems. For limitation, the findings require caution for generalizability to older caregivers with uncontrolled conditions or impaired physical and cognitive functions. Thus, further replication is needed.

VI. CONCLUSION

Most of the older caregivers had little or no overall caregiving burden. Guilt was a subdomain perceived as mild to severe by the majority of older persons. Stroke survivors’ physical function and older caregivers’ self-esteem could predict caregiving burden. The finding can be applied for developing rehabilitation programs to prevent and decrease caregiving burden by improving physical function of stroke survivors, and enhancing self-esteem of older caregivers.

REFERENCES


