Comparison of Psychological Health Problems between Families Living with Stroke Survivors and the General Population in the Community

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This study aimed to identify and assess the differences in psychological health problems between families living with stroke survivors (FwSS) and the general population without stroke families (GwoSF). A total of 4,514 cases of FwSS were selected for analysis from the 2013 Korea Community Health Survey. In order to determine control groups in GwoSF, propensity scores were generated based on the sociodemographic characteristics of age, gender, residential region, marital status, educational level, monthly household income, and employment status. Each FwSS was matched to 3 controls of GwoSF (13,542 controls) using a greedy matching algorithm with 8 to 1 digit matching. After propensity score-matching, the proportion of usual stress (30.2% vs 24.6%), depressive mood (7.1% vs 6.1%), and suicidal ideation (13.0% vs 11.1%) in FwSS were all significantly higher than those in GwoSF (Ps<0.05). Compared to GwoSF, the adjusted odds ratios (aORs) with 95% confidence intervals (CIs) for psychological health problems in FwSS were calculated using multiple logistic regression analysis. The aORs for usual stress (aOR 1.32, 95% CI 1.21–1.42), depressive mood (aOR 1.14, 95% CI 0.99–1.31; borderline significance), and suicidal ideation (aOR 1.17, 95% CI 1.05–1.30) were significantly higher among FwSS than GwoSF. Moreover, the psychological health problems of FwSS were more evident in females than in males. This study shows that FwSS have poorer psychological health outcomes than GwoSF with similar sociodemographic characteristics. Community-based strategies and family support programs, especially for female family members of stroke survivors, are essential to improve the psychological health of stroke families.

Key Words: Stroke; Family; Mental Health; Depression; Suicidal Ideation

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INTRODUCTION

Stroke is an important public health issue in the world as it is the second leading cause of death and the third most common cause of disability globally.¹,² Korea’s latest data show that stroke deaths account for 7.7% of all deaths and are the fourth leading cause of death in the country.³ The number of patients surviving with stroke-related disabilities have been increasing in recent years as the population ages and as medical technology around acute stroke care advances.⁴

Stroke necessitates significant caregiving support for rehabilitation and general care due to ongoing functional and cognitive impairments.⁵ The majority of stroke survivors are discharged home,⁶,⁷ so the need for provision of informal care by family members of stroke survivors increases. Family caregiving still remains the backbone of rehabilitation services in the community. Every family member involved in helping a stroke survivor—such as their spouse, offspring, parents, or other relatives—are known as family caregivers. Some family members of stroke patients may not consider themselves as caregivers, but the term 'family
caregiver’ is generally used to refer to the family or even informal caregivers. Family caregivers are an important and major source of providing care for stroke survivors, and they are critical to the care and recovery of community-dwelling stroke survivors. Because the caregiver’s role comes unexpectedly, family caregivers are usually unprepared and experience negative consequences on health status and quality of life. The transition from acute in-patient caregiving to home caregiving after a stroke patient is discharged has a great impact on family caregivers of the stroke survivor. Although there is a difference in the degree and duration of caregiving participation in the health care process, almost all family members of stroke patients are exposed to various physical, psychological, social, and economic problems. Stroke caregiving is highly stressful and can contribute to the development of psychological problems (e.g., depression) in family caregivers, because informal caregivers of stroke patients are given a sudden caregiving roles compared to the gradual increase in the burden of care for cancer or dementia patients.

However, as of now, little is known about the psychological status of stroke family members compared to that of the general population. Therefore, in this study, we determined and compared psychological health problems such as perceived usual stress, depressive mood, and suicidal ideation of families living together with stroke survivors (FwSS) with the general population without stroke families (GwoSF). We also examined the gender differences in the psychological health problems associated with living with or without stroke survivors.

MATERIALS AND METHODS

1. Study population

Cross-sectional data from the 2013 Korean Community Health Survey conducted by the Korea Centers for Disease Control and Prevention were used for this study. After multistage, stratified random sampling was used to select representative households, a total of 228,781 individuals aged 19 years or older were included in the 2013 survey. Of these, 4,560 were community-living stroke survivors and 4,695 were FwSS, which was defined as people living with a stroke patient at home at the time of the survey. After excluding participants for whom any sociodemographics, health behavior, and/or health status data were missing, 4,514 cases of FwSS were included in the final analysis. To determine the controls of families without stroke, propensity scores were generated based on seven sociodemographics including age, gender, residential region, marital status, educational level, monthly household income, and employment status. Each FwSS was matched to three controls of GwoSF using the greedy matching algorithm with 8- to 1-digit matching. According to this algorithm, a GwoSF is first matched to a FwSS based on the first 8 digits of the propensity score of FwSS. If there was no exact match, the controls were matched using 7 digits, 6 digits, 5 digits, and so on. Finally, 211,403 controls of GwoSF were selected before propensity score-matching (PSM) application and 13,542 controls of GwoSF were selected after 1:3 PSM application. This study was carried out in accordance with all relevant guidelines of the Declaration of Helsinki. Our study protocol was approved by the Institutional Review Board of the Wonkwang University Hospital (WKUH 2020-01-013-002).

2. Measures

The dependent variables compared between FwSS and GwoSF were psychological health indicators including usual stress, depressive mood, and suicidal ideation. Perceived usual stress level was evaluated by asking the participant a question (“How much stress have you felt during your daily life over the past year?”) and selecting one of the four response options (feels very much, feels much, feels a little, or barely feels). High perceived usual stress was defined as feeling very much or much stress in daily life. Experience with depressive mood was defined as feeling sad or desperate for more than 2 weeks in a row during the past year. Experience with suicidal ideation was defined as having thoughts of wanting to die in the past year.

The sociodemographic factors included age (19-44, 45-64, 65-74, or ≥75 years), gender (male or female), residential region (urban or rural), marital status (married, never married, divorced/separated, or widowed), educational level (non-formal education, primary school, middle or high school, or college and higher), monthly household income ($0, $1,012, 2,014, or ≥4,011,000 KRW), and employment status (employed, unemployed, or housewife/student). Health behaviors included smoking status (never, former, or current smoker), frequency of alcohol use (none, ≤1 time-, 2-3 times-, or ≥4 times per week), and walking activity (≤2 times or ≥3 times per week). Diagnosis of hypertension and diabetes were classified as having been diagnosed or never diagnosed.

3. Statistical analysis

The characteristics of FwSS and GwoSF were compared using the chi-square test for categorical variables and analysis of variance for continuous variables, before and after PSM. The proportion of having psychological health problems (usual stress, depressive mood, and suicidal ideation) were compared between FwSS and GwoSF. After PSM, a multiple logistic regression analysis was used to evaluate the whether or not there was an association between FwSS and psychological health problems. Model 1 was unadjusted and model 2 was adjusted for health behaviors and diagnosis of chronic diseases in addition to the sociodemographic factors. Finally, model 3 was further adjusted for social participation (religious activity, friendship activity, leisure activity, charitable activity), socio-family relationship (family contact, neighbor contact, friend contact), EuroQol-Visual Analogue Scale, self-rated health, and sleep duration. Compared to GwoSF, the odds ratio (OR) with 95% confidence intervals (CIs) of FwSS was calculated. All statistical analyses were performed with the
RESULTS

1. Characteristics of the study population
   The distribution of the characteristics of GwoSF before and after PSM are presented in Table 1 together with the comparison of characteristics between FwSS and GwoSF. Before matching with PSM, there were significant differences in sociodemographic characteristics between FwSS and GwoSF. The FwSS were more likely than GwoSF (before PSM) to be older, to be female, to live in a rural area, to be married, to have a lower educational level, to have a lower monthly household income, and to be unemployed or a housewife or student (p<0.001). However, after matching with PSM, no significant difference in sociodemographic characteristics between FwSS and GwoSF was found.

   Health behaviors such as smoking status and frequency of alcohol use, and diagnosis of chronic diseases such as hypertension and diabetes mellitus were different between FwSS and GwoSF before matching. However, after matching, no significant difference of health behaviors and diagnosis of diabetes mellitus (not hypertension) between the FwSS and GwoSF was observed.

2. Comparison of psychological health problems between FwSS and GwoSF
   The proportion of high usual stress and experience with suicidal ideation was persistently higher among FwSS than GwoSF. Nevertheless, after matching, no significant difference of health behaviors and diagnosis of diabetes mellitus (not hypertension) between the FwSS and GwoSF was observed.

3. Association between FwSS, GwoSF, and psychological health problems
   Table 3 shows the ORs and 95% CIs for the associations between living together with stroke survivors and psychological health problems adjusted analysis (OR 1.16, 95% CI 1.08-1.24).

4. Association between FwSS, GwoSF, and psychological health problems by gender
   Table 4 shows the fully-adjusted ORs and 95% CIs for the associations between living together with stroke survivors and psychological health problems by gender. Compared with GwoSF, high perceived usual stress was significantly higher among FwSS both in males (OR 1.17, 95% CI 1.08-1.26) and females (OR 1.42, 95% CI 1.33-1.51) (p interaction<0.001). Experience with depressive mood was significantly higher among FwSS than GwoSF in females (OR 1.22, 95% CI 1.10-1.35), but not in males (OR 0.96, 95% CI 0.81-1.13) (p interaction<0.001). In addition, experience with suicidal ideation was also significantly higher among FwSS than GwoSF in females (OR 1.20, 95% CI 1.10-1.30), but not in males (OR 1.10, 95% CI 0.98-1.24) (p interaction<0.001).

DISCUSSION

After matching using PSM to achieve sociodemographic characteristics comparability, this study found that FwSS have poorer psychological health outcomes such as perceived usual stress, depressive mood, and suicidal ideation than GwoSF. Moreover, the psychological health problems including perceived usual stress, depressive mood, and suicidal ideation of FwSS were more apparent in females than in males.

This study identified that FwSS had stress and depressive symptom frequencies of about 1.3 times and 1.2 times higher than GwoSF with similar sociodemographic characteristics, respectively. Even with paid formal support, FwSS frequently face a variety of stressors—from coordination of medical care to 24-hour daily care of patients.14 Family caregivers suddenly need to assist and support stroke survivors with their daily activities such as meal preparation, feeding, dressing, cleaning, bathing, toileting, mobilization, and transportation.15 Evidence showed that caregiving of stroke patients is highly stressful and leads to clinically significant depression in caregivers.13 Depression is common in both stroke survivors and family caregivers.13,16-18 Furthermore, stroke survivors and family caregivers mutually influence each other’s depressive symptoms. Depressive symptoms in stroke survivors are associated with depression of their family caregivers,19 while depression of caregivers influences post-stroke depression and negatively affects the rehabilitation process of stroke patients.20-22 Some studies have even reported that the prevalence of depression among family caregivers is higher than in the stroke patients they care for.16,17

Although many studies have examined suicidal ideation in stroke patients including Korea,23-25 few studies have investigated and compared the suicidal ideation of stroke family caregivers to the general public. The present study showed that FwSS had higher risks of suicidal ideation than GwoSF with similar sociodemographic characteristics.
| Variable                  | General population without stroke families                      | Families living together with stroke survivors | p-value       |
|---------------------------|------------------------------------------------------------------|-----------------------------------------------|---------------|
|                           | Before PSM* (n=211,403)                                         | After PSM† (n=13,542)                         |               |
| Age                       | 51.5±17.0                                                        | 57.2±17.3                                     | <0.001        |
| Age group                 |                                                                  |                                               | 0.951         |
| 19-44 years               | 77,599 (36.7)                                                   | 3,449 (25.5)                                  | <0.001        |
| 45-64 years               | 79,904 (37.8)                                                   | 4,417 (32.6)                                  | <0.001        |
| 65-74 years               | 32,471 (15.4)                                                   | 3,394 (25.1)                                  | <0.001        |
| ≥75 years                 | 21,429 (10.1)                                                   | 2,282 (16.9)                                  | <0.001        |
| Gender                    |                                                                  |                                               | 0.991         |
| Male                      | 94,975 (44.9)                                                   | 5,649 (41.7)                                  | <0.001        |
| Female                    | 116,428 (55.1)                                                  | 7,893 (58.3)                                  | <0.001        |
| Residential region        |                                                                  |                                               | 0.938         |
| Urban                     | 120,294 (56.9)                                                  | 6,144 (45.4)                                  | <0.001        |
| Rural                     | 91,109 (43.1)                                                   | 7,398 (54.6)                                  | <0.001        |
| Marital status            |                                                                  |                                               | 0.962         |
| Married                   | 144,364 (68.3)                                                  | 10,227 (75.5)                                 | <0.001        |
| Never married             | 31,528 (14.9)                                                   | 2,324 (17.2)                                  | <0.001        |
| Divorced or separated     | 11,391 (5.4)                                                    | 552 (4.1)                                     | <0.001        |
| Widowed                   | 24,120 (11.4)                                                   | 439 (3.2)                                     | <0.001        |
| Educational level         |                                                                  |                                               | 0.981         |
| Non-formal education      | 15,980 (7.6)                                                    | 1,470 (10.9)                                  | <0.001        |
| Primary school            | 37,581 (17.8)                                                   | 3,863 (28.5)                                  | <0.001        |
| Middle or high school     | 85,246 (40.3)                                                   | 5,258 (38.8)                                  | <0.001        |
| College and higher school | 72,596 (34.3)                                                   | 2,951 (21.8)                                  | <0.001        |
| Monthly household income  |                                                                  |                                               | 0.994         |
| ≤1 million KRW            | 50,328 (23.8)                                                   | 5,085 (37.5)                                  | <0.001        |
| 1.01-2 million KRW        | 39,437 (18.7)                                                   | 2,897 (21.4)                                  | <0.001        |
| 2.01-4 million KRW        | 66,689 (31.5)                                                   | 3,302 (24.4)                                  | <0.001        |
| ≥4.01 million KRW         | 54,949 (26.0)                                                   | 2,258 (16.7)                                  | <0.001        |
| Employment status         |                                                                  |                                               | 0.358         |
| Employed                  | 135,000 (63.9)                                                  | 7,771 (57.4)                                  | <0.001        |
| Unemployed                | 26,669 (12.6)                                                   | 2,147 (15.9)                                  | <0.001        |
| Housewife or student      | 49,734 (23.5)                                                   | 3,624 (26.8)                                  | <0.001        |
| Smoking status            |                                                                  |                                               | 0.872         |
| Never smokers             | 133,434 (63.1)                                                  | 8,928 (65.9)                                  | <0.001        |
| Former smokers            | 34,721 (16.4)                                                   | 2,218 (16.4)                                  | <0.001        |
| Current smokers           | 43,248 (20.5)                                                   | 2,396 (17.7)                                  | <0.001        |
| Frequency of alcohol use  |                                                                  |                                               | 0.053         |
| None                      | 69,271 (32.8)                                                   | 5,654 (41.8)                                  | <0.001        |
| ≤1 time per week          | 96,366 (45.6)                                                   | 5,375 (39.7)                                  | <0.001        |
| 2-3 times per week        | 29,624 (14.0)                                                   | 1,510 (11.2)                                  | <0.001        |
| ≥4 times per week         | 16,142 (7.6)                                                    | 1,003 (7.4)                                   | <0.001        |
| Walking activity          |                                                                  |                                               | 0.577         |
| ≤2 times per week         | 76,132 (36.0)                                                   | 5,124 (37.8)                                  | <0.001        |
| ≥3 times per week         | 135,271 (64.0)                                                  | 8,418 (62.2)                                  | <0.001        |
| Diagnosis of hypertension|                                                                  |                                               | 0.033         |
| No                        | 162,398 (76.8)                                                  | 9,460 (69.9)                                  | <0.001        |
| Yes                       | 49,005 (23.2)                                                   | 4,082 (30.1)                                  | <0.001        |
| Diagnosis of diabetes     |                                                                  |                                               | 0.457         |
| No                        | 192,971 (91.3)                                                  | 12,010 (88.7)                                 | <0.001        |
| Yes                       | 18,432 (8.7)                                                    | 1,532 (11.3)                                  | <0.001        |

Data are presented as number (percentage) or mean±standard deviation.
PSM: propensity score-matching.
The high level of psychological problems such as stress, anxiety, and depression favored the increased risk of suicidal ideation among caregivers of stroke patient.\textsuperscript{27} Prolonged suffering from caregiving makes the caregivers more vulnerable to emotional stress and feelings of frustration, hopelessness and worthlessness, may result in depression and suicidal ideation.\textsuperscript{28,29} Numerous studies showed effective interventions for stroke caregivers and it has been shown that interventions for stroke family caregivers can improve stroke patient as well as caregiver outcomes.\textsuperscript{3} Previous studies have reported that stroke caregiver intervention significantly improved caregiver’s preparedness, knowledge, burden, stress, strain, anxiety, depressive symptoms, and quality of life.\textsuperscript{8}

### Table 2. Psychological health problems between families living together with stroke survivors and the general population without stroke families

| Variable            | General population without stroke families (after PSM) | Families living together with stroke survivors | p-value |
|---------------------|--------------------------------------------------------|-----------------------------------------------|---------|
| Perceived usual stress | Low: 11,212 (75.4) 3,149 (69.8)               | High: 3,330 (24.6) 1,365 (30.2)               | <0.001  |
|                     | Depressive mood                                      |                                               | 0.011   |
|                     | No: 12,270 (93.9) 4,192 (92.9)                      | Yes: 822 (6.1) 322 (7.1)                     | <0.001  |
| Suicidal ideation   | No: 12,045 (88.9) 3,925 (87.0)                      | Yes: 1,497 (11.1) 589 (13.0)                 |         |

Data are presented as number (percentage). PSM: propensity score-matching.

In addition, although not all studies have shown consistent results, many studies have shown that stroke caregiver intervention is effective in improving anxiety, depression, quality of life, and physical and social function in stroke survivors.\textsuperscript{8} Psychological interventions and psychoeducation of stroke caregivers are useful and efficient in reducing the caregiver’s psychological problems and burdens.\textsuperscript{30,31} Thus, psychological interventions should be integrated as part of the stroke rehabilitation process to improve the quality of life and well-being of patients and caregivers.\textsuperscript{32} Consistent with a systematic review of stroke family caregivers,\textsuperscript{33} intervention studies that incorporate skill building (problem solving, stress management, goal setting, etc.) with psychoeducational strategies more effectively improved caregiver and survivor outcomes than psychoeducation alone. Also, interventions that directly target stroke caregivers are more effective in improving caregiver outcomes than caregiver/stroke survivor dyad interventions.\textsuperscript{8} The educational program regarding home care for stroke family caregivers was effective in improving knowledge and practice for the caregiving of stroke patients and contributing family caregivers to be prepared for home caregiving after discharge.\textsuperscript{33} Family caregivers may have difficulty coping with new roles and accessing community support services, especially during the transition period from hospital to home. Therefore, programs for education and training to manage their new responsibilities and to identify community support resources are needed.\textsuperscript{34} Also, community-based stroke family support and reeducation programs are necessary to reduce caregiver burden and improve coping strategies for the family caregivers of stroke survivors.\textsuperscript{34}

The degree to which caregiving is perceived as a burden may vary between society and culture, based on the cultural orientation toward familism and individualism.\textsuperscript{35} Cultural backgrounds of caregivers may affect how they

### Table 3. Odds ratios and 95% confidence intervals for the associations between living together with stroke survivors and psychological health problems (determined using multivariate logistic regression analysis)

| Variable                                      | Model 1                       | Model 2                       | Model 3                       |
|------------------------------------------------|-------------------------------|-------------------------------|-------------------------------|
| High perceived usual stress                   | 1.00 (reference)              | 1.00 (reference)              | 1.00 (reference)              |
| General population without stroke families (after PSM) | 1.33 (1.27-1.39)             | 1.33 (1.27-1.39)             | 1.31 (1.25-1.38)             |
| Families living together with stroke survivors |                               |                               |                               |
| Experience with depressive mood               | 1.00 (reference)              | 1.00 (reference)              | 1.00 (reference)              |
| General population without stroke families (after PSM) | 1.19 (1.10-1.30)             | 1.19 (1.09-1.29)             | 1.13 (1.04-1.23)             |
| Families living together with stroke survivors |                               |                               |                               |
| Experience with suicidal ideation             | 1.00 (reference)              | 1.00 (reference)              | 1.00 (reference)              |
| General population without stroke families (after PSM) | 1.21 (1.14-1.29)             | 1.21 (1.13-1.29)             | 1.16 (1.08-1.24)             |
| Families living together with stroke survivors |                               |                               |                               |

Data are presented as odds ratio (confidence interval). PSM: propensity score-matching.

Model 1 was unadjusted.

Model 2 was adjusted for smoking status, frequency of alcohol use, walking activity, diagnosis of hypertension, and diagnosis of diabetes.

Model 3 was further adjusted for social participation (religious activity, friendship activity, leisure activity, charitable activity), socio-family relationship (family contact, neighbor contact, friend contact), EuroQol-Visual Analogue Scale, self-rated health, and sleep duration plus model 1.
cope with the demands of caregiving for stroke patients. A previous cross-cultural study indicated that Korean caregivers may be more depressed and have higher burden than those in the United States, as nursing homes and daycare centers for stroke patients are less available than those in the United States, because nursing homes caregivers may be more depressed and have higher burden..

This study has some limitations to consider. First, the cross-sectional design of this study cannot infer causality. Second, since information on psychological health status was collected retrospectively via self-reporting, it is possible that there was a recall bias. Third, our study included only families of community-living stroke survivors, but did not include families of in-hospital patients with acute or severe strokes. Thus, the impact of living with stroke survivors on psychological health may be underestimated. Fourth, more specific measures were not used in this study to evaluate care burden or psychological distress of family members. Fifth, there will be some difference in the characteristics between family caregiver and just cohabiting family. However, we could not identify whether each family member cared for the stroke patient, so the entire families living with stroke survivors was analyzed. Lastly, since it was not possible to confirm the presence of other chronic diseases (dementia, cancer, etc.) requiring care in the family, even these chronic disease families would not have been excluded from the control groups. Nevertheless, this study has several strengths. First, GwoSF was chosen as the comparison group of FwSS, and the PSM made the sociodemographic characteristics of the comparison group similar to FwSS. It is difficult to determine the extent of psychological health problems of FwSS without comparison with GwoSF, which has similar sociodemographic characteristics. Second, this study included all family caregivers, not only the main caregiver but also other family members who live together with the stroke survivors. Third, there have been many studies on the caregivers of stroke inpatients, but only a few studies on the family caregivers of stroke survivors in the community setting. This study showed that stroke families have poorer psychological health states than the general population with similar sociodemographic characteristics to them. It has also been shown that many stroke survivors and their family caregivers feel abandoned after hospital discharge.

| Variable | Male | Female |
|----------|------|--------|
| High perceived usual stress | 1.00 (reference) | 1.00 (reference) |
| Families living together with stroke survivors | 1.17 (1.08-1.26) | 1.42 (1.33-1.51) |
| Gender-stroke families (p for interaction) | 0.101 |
| Experience with depressive mood | 1.00 (reference) | 1.00 (reference) |
| Families living together with stroke survivors | 0.96 (0.81-1.13) | 1.22 (1.10-1.35) |
| Gender-stroke families (p for interaction) | 0.145 |
| Experience with suicidal ideation | 1.00 (reference) | 1.00 (reference) |
| Families living together with stroke survivors | 1.10 (0.98-1.24) | 1.20 (1.10-1.30) |
| Gender-stroke families (p for interaction) | 0.326 |

Data are presented as odds ratio (confidence interval).

PSM: propensity score-matching

Adjusted for smoking status, frequency of alcohol use, walking activity, diagnosis of hypertension, diagnosis of diabetes, social participation (religious activity, friendship activity, leisure activity, charitable activity), socio-family relationship (family contact, neighbor contact, friend contact), EuroQol-Visual Analogue Scale, self-rated health, and sleep duration.
in their communities. Community-based strategies and family support programs, especially for female FwSS, are essential to improve the psychological health of families living together with stroke patients.

ACKNOWLEDGEMENTS

This paper was supported by Wonkwang University in 2020.

CONFLICT OF INTEREST STATEMENT

None declared.

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