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Comparing Perceived Burden for Korean and American Informal Caregivers of Stroke Survivors

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Abstract

Little is known about the burden of caring for stroke patients cross-culturally. This article compares the perceived burden for caregivers of stroke survivors in Korea and the United States. A brief interview was conducted to determine specific problem areas for caregivers. Caregiver burden (The Sense of Competence Questionnaire) and social support (The ENRICH Social Support Inventory) were also measured. Overall sense of burden from caregiving was higher in the Korean cohort than in the Seattle cohort. The primary predictors of overall burden were caregiver and patient depression, and insufficient social support. The lower perceived social support among the Korean caregivers may reflect changes in Korean culture with lack of social support outside the family. American caregivers were more often troubled by lack of time for themselves. These findings may inform rehabilitation nurses in planning supportive interventions for stroke survivors and their caregivers that attend to cultural values.

Keywords

Care givers; Stroke; Cultural Issues; Depression; Social Support; fatigue

Introduction

Caring for stroke survivors can be burdensome for their informal caregivers, with additional burden perceived when caring for stroke survivors with emotional problems (Han & Haley, 1999; Choi-Kwon, Kim, Kwon & Kim, 2005; Clark, 2006; Clark, Dunbar, Aycock, Courtney & Wolf, 2006; Pierce, Steiner, Hicks & Holzaepfel, 2006). Although there is extensive literature evaluating caregiver burden and benefit in stroke patients (Morimoto, Schreiner & Asano, 2003; Mant, Winner, Roche & Wade, 2005; McCullagh, Brigstocke, Donaldson & Kalra, 2005; Tooth, McKenna, Barnett, Prescott & Murphy, 2005; van Exel, Koopmanschap, van den Berg, Brouwer & van den Bos, 2005) there has been little comparison of informal caregiver burden across cultures for any chronic condition.

The degree to which caregiver work is perceived as a burden may differ among different societies and cultures, depending on cultural ideas of familism and individualism (Youn, Knight, Jeong & Benton, 1999; Morimoto et al., 2003). In Korea, Confucian ideology places the eldest male at the head of the family, receiving loyalty from his offspring. In addition, societal supports, such as nursing homes or therapeutic day care for patients with chronic illness are generally less available in Korea than in the United States (Grant, Bartolucci, Elliot & Giger, 2000). Therefore, care for a chronic illness such as stroke in an elderly family member may exert a considerable amount of burden on female caregivers, particularly daughters-in-law (Choi-Kwon, Kim et al., 2005). In Western countries, on the other hand, individualism predominates. The caregivers in Seattle where Western European-American culture dominates may feel loss of time and privacy more burdensome than the caregivers in Seoul.

The effect of ethnicity and culture on the caregiving experience, however, has most commonly been measured in caregivers of people with dementia of the Alzheimer's type, but usually within a given culture, rather than cross-culturally. Youn and colleagues compared Korean, Korean American and United States (US) Caucasian informal caregivers of people with dementia in terms of familism and caregiver burden. (Youn et al., 1999) They found, as expected, that familism was highest in Korean caregivers and lowest in US Caucasians, with Korean Americans in the middle. Contrary to their hypothesis, perceived caregiver burden was highest in Koreans and Korean Americans, with Koreans caregivers reporting higher levels of

depression and of anxiety than the other groups. No comparable studies were yet found with respect to cross-cultural comparisons in caregivers of stroke survivors.

The fact that our two separate research groups used common measures of caregiver burden in Korean and US depressed stroke survivors provided an opportunity to compare factors related to caregiver burden in two cultures. The parent studies did not have a common conceptual framework but we used an identical analytic framework for the comparison to assess perceived burden for partners of community-dwelling stroke survivors (Scholte op Reimer, de Haan, Pijnenborg, Limburg & van den Bos, 1998; Scholte op Reimer, de Haan, Rijnders, Limburg & van den Bos, 1998).

Social support was an inferred but unmeasured component of the SCQ framework. Social support may be a buffering factor in increasing the stroke caregiver's emotional well-being and moderating the depression often seen following life-changing illness of significant others (Glass, Matchar, Belyea & Feussner, 1993; Youn et al., 1999; Grant et al., 2000; Hong et al., 2000; Yoon, Cha & Cho, 2000; Sit, Wong, Clinton, Li & Fong, 2004; Mant et al., 2005; Egbert, Koch, Coeling & Ayers, 2006). Relatively little study has been conducted into social support and its relation to caregiver burden. We did not locate any that compared social support for the caregivers of stroke survivors in Western and Asian countries.

We, therefore, conducted independent studies in Korea and the US of emotional distress in urban stroke survivors and their caregivers. Each study used the same instruments to measure caregiver burden and social support. These studies provided an opportunity to explore the relationship among several variables known to influence caregiver burden in western cultures between social support and caregiver burden for stroke survivors.

THE STUDY

Aims

The purpose of this analysis was to compare the perceived burden of Korean and American informal caregivers of ischemic stroke survivors and to identify the factors affecting caregiver burden in two different cultures.

Design

This was a descriptive comparison design using data collected at entry to two independent studies of treatment of post-stroke emotional distress.

Participants—Participants who provided data for this analysis were enrolled in the primary studies in cities in the US (Seattle, Washington) and in Korea (Seoul). The Seattle participants comprised 33 ischemic stroke survivors and their caregivers who were enrolled in a study of post-stroke depression (PSD) between December 2002 and October 2005.

The Participants from Seattle were stroke patients with clinical depression (as measured by the Diagnostic Interview and Structured and Hamilton (DISH) (Freedland et al., 2002) who were enrolled in the parent study, a randomized trial of a behavioral intervention. At the baseline period, after randomization but prior to intervention(4 months post-stroke), partners of the stroke survivor were given questionnaires to measure the impact of stroke caregiving.

The participants from Seoul were enrolled between December 2003 and August 2004. Stroke survivors who attended the outpatient clinic at a large academic medical center were interviewed for the presence of post-stroke depression (PSD). The interview was performed an average of 14 months after the onset of stroke by one of researchers. Forty-one patients and caregivers agreed to participate and these pairs are included in this analysis. The primary

outcomes of the clinical trial have been reported (Choi-Kwon, Han, Kwon, Kang, Choi & Kim, 2006), but the data used in this analysis have not been previously published.

Ethical Considerations—Each parent study was approved by the respective institutional review board in accordance with the Helsinki principles, and included authority to release non-identifiable data for secondary analyses. All the enrolled patients and caregivers gave informed consent.

Methods

Data collection Instruments and procedure—Both sites collected data used for this analysis from stroke survivors and informal caregivers at entry to the parent treatment trial. Data was collected with structured questionnaires and structured interviews performed by trained research nurses, whose interviewing consistency was overseen by the project coordinator and principal investigator in each research group. Data collection occurred at an average of 14 months after the onset of stroke in the Korean population and within 4 months after the stroke in the US group. This data collection occurred prior to any intervention in both studies such that results are not influenced by the differing treatments in the main studies. We compared the Seattle cohort caregiver burden scores for entry and 12 months following stroke and found no statistically significant difference. We therefore elected to use the entry scores to maximize numbers and avoid any potential confounding by intervention effects.

To avoid any possibility that presence of the patients might influence the caregivers to modify their responses regarding the burden, the caregivers' perceived burden was assessed in the absence of the patients after all the patients' information was obtained (Choi-Kwon, Kim et al., 2005).

Stroke survivor data—Clinical and functional data about the stroke survivor included age, gender and other demographic data, history of stroke, depression and other co-morbidities, including impairment in functional ability (NIH stroke scale, Barthel index). Current employment status following stroke was also recorded.

Informal Caregiver Demographic and Caregiving Data—A primary informal caregiver was defined as 'a person who lives with the patient and is most closely involved in taking care of him/her at home' (Choi-Kwon, Kim et al., 2005). Demographic data regarding the primary caregiver, information regarding the presence of an alternative caregiver, hours of care/day, the most challenging tasks performed for the patient, the relationship of the caregiver to patients, and self-rated global health status of the caregiver before and after the occurrence of patient's stroke was obtained using the same structured interview in both studies.

Social support of caregivers—Social support for the caregivers in both studies was assessed using the ENRICHED Social Support Instrument (ESSI), which comprises 6 items with scores of 1 to 5 plus an item regarding marital status. This instrument measures structural, instrumental, and emotional support, but not social networks. The score ranges from 8 to 34, the higher scores indicating greater social support (Mitchell et al., 2003).

Caregiver burden—While many instruments are used to assess caregiver burden and benefits, few have been used frequently or in cross cultural comparisons (Visser-Meily, Post, Riphagen & Lindeman, 2004). We used English and Korean translations of the Sense of Competence Questionnaire (SCQ) (Scholte op Reimer, de Haan, Pijnenborg et al., 1998; Choi-Kwon, Kim et al., 2005). The SCQ provides subscale and overall scores for perceived burden and benefit in three sub domains with a total of 27 items, each on a four-point scale. Sub domain 1 has 7 items indicating satisfaction with the impaired person as a recipient of care; sub domain

2 has 12 items indicating satisfaction with one's own performance as a caregiver, and sub domain 3 with 8 items indicating consequences of involvement in care for the personal life of the caregiver. The overall scores for total and the sub domains were represented as mean of each score, ranging from 1 to 4; the higher the score, the higher the burden. We selected this instrument because the relative contributions of both patients' and caregivers' characteristics to the burden of caregiving are included, and because it has been tested specifically with stroke survivors and their partners. To our knowledge, this is the first cross-cultural comparison with this instrument.

Caregiver/Partner Mood—In the Seattle sample, depressive mood was evaluated with the Geriatric Depression Scale (GDS) in both stroke survivors and caregivers (Brink, 1982; Yesavage et al., 1982; Brink, 1989). The GDS is a 30-item scale in a yes/no format, which typically takes about 10 minutes. Scores of 0–10 indicates normal mood; 11–20 is mild/moderate depression; 21–30 equals severe depression. For analytic purposes, caregivers who scored ≥ 11 on the GDS were classified as depressed. Stroke survivors who scored 11 or above were further evaluated with DSM IV criteria in order to enter the parent study of treatment for post-stroke depression. Thus the Seattle informal caregivers in this analysis are all partnered with a stroke survivor who met DSM IV criteria for clinical depression.

In the Seoul caregivers, the Hospital Anxiety and Depression (HAD) Scale was used (Zigmond & Snaith, 1983). It consists of 14 items (seven for anxiety and seven for depression), each measured on a 4-point scale. Depression or anxiety was considered to be present if the caregivers had a score ≥ 10 in depression or in anxiety inventory, respectively. Scores between eight and ten were considered borderline. For analytic purposes, those patients with borderline depression/anxiety were categorized as having depression/anxiety. In the Korean stroke survivors, PSD was considered to be present when either the Diagnostic and Statistical Manual, 4th edition criteria or the Beck Depression Inventory (BDI) score was > 13 were met (Choi-Kwon, Choi, Kwon, Kang & Kim, 2006; Choi-Kwon, Han et al., 2006).

Analysis—Data from the two studies were merged into an SPSS data file. All Korean responses were represented in English, with any ambiguous translations verified by the Korean principal investigator. Responses were described by group using percentages, means and standard deviations. Group mean scores on the burden instrument were compared with ANOVA, and predictors of burden were analyzed with multiple linear regression.

Results

Characteristics of stroke survivors and caregivers—Participants were 41 stroke survivor/informal caregiver pairs from Korea and 33 pairs from the US. Among the 41 stroke survivors from Korea, 12 were classified as depressed and 29 were not. The stroke survivors from the US were all depressed since this was a criterion for entry into the Seattle study.

As shown in Table 1, the characteristics of stroke survivors among the three groups were similar except for marital status (Seattle more likely to be divorced or single), years of education (Seattle more highly educated), employment status (Seoul more likely to be employed) the presence of diabetes mellitus (greater in Seattle), and the Barthel Index of current disability (lower disability in Seoul). The mean age of the both stroke survivors and caregivers ranged from the 52 to nearly 62. The majority of the stroke survivors in both sites were male, while caregivers were predominantly female.

Caregiver characteristics are shown in Table 2. The caregivers in the Seattle depressed stroke survivor group were more educated than were the Korean caregivers. The caregivers in Seoul's undepressed stroke survivors group were more often employed than those of depressed stroke survivors in Seoul and Seattle. Korean caregivers were more likely than Seattle caregivers to

indicate that their health had deteriorated from excellent or good to fair after the patient's stroke. Caregivers in Seoul were more often classified as depressed (more than 50% versus 37%), had lower ESSi mean score (17–19 versus 22), less likely to provide >15 hours of caregiving per day (14–17% versus 23%), and had a higher mean burden score (2.8 versus 2.3) as compared to the caregivers in the Seattle depressed stroke survivors.

Caregiver burden—The mean overall burden score was 2.8, 2.5, 2.3 in the informal caregivers of Seoul's depressed, Seoul's not depressed, and Seattle's depressed stroke survivors, respectively. There was a statistically significant difference among groups only in the satisfaction with relationships ($F 2.47$, $df 7$, $p=0.027$) with both Korean caregiver groups endorsing greater burden scores than the Seattle group. The scores for subscales and for each item are shown in table 3.

The most challenging things in caring for stroke survivors—For both Seattle and Seoul caregivers, dealing with the patients' anger and mood were the most challenging things in caring for patients with depression (Table 4). Informal caregivers in Seoul more often felt that they had higher economic burden and more worry about the patient illness than did their counterparts in Seattle. Dealing with the patients' fatigue was reported by Seoul caregivers more often to be the one of the most challenging things.

Factors related to caregiver burden and caregiver depression—To understand the relative contributions of patient and caregiver factors in determining perceived caregiver burden, we performed multiple regression analysis, choosing variables from our dataset known to be related to burden in the literature. The best model explained about 39% of the variance in total burden score and included measures of hours of caregiving, caregiver social support, caregiver age, caregiver education, patient disability, patient depression, caregiver depression, and location (Seattle or Seoul) ($R = 0.675$, $R \text{ square} = 0.456$, adjusted $R \text{ square} = 0.386$, $R \text{ square change} = 0.456$, $F \text{ change} 6.498$, $df 8, 62$, $p = 0.000$)

Univariate relationships for each cohort that were statistically significant include the following. In Seoul, the greater the caregiver education, the lower the overall burden score ($r = -0.337$, $p < .05$) while in Seattle this association was more modest and nonsignificant ($r = 0.273$). Less social support in Seoul was strongly associated with the caregiver being depressed ($r = -0.619$, $p < .01$, $N=41$), whereas lower social support in Seattle was moderately related to increased hours of care giving ($r = -0.484$, $p < .05$, $N=33$), while higher social support was associated with increased caregiver age ($r = 0.398$, $P < .05$). In Seattle, the greater the hours of care giving, the greater the total burden score ($r = 0.51$, $p < .01$), and the more likely the caregiver was to be depressed ($r = 0.305$, $p < .05$). In Seoul, the hours of care giving were strongly related to greater patient disability ($r = -0.749$, $p < .01$), accounted for by the small number of Korean stroke survivors who still had significant motor disability at 14 months post-stroke.

Discussion

This is the first comparison of burdens of urban informal caregivers of stroke survivors with emotional dysfunction across Korean and US cultures.

Although the emotion was reported to be related to caregiver burden (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002; Choi-Kwon, Kim et al., 2005; Clark et al., 2006), Seoul caregivers reported higher burden than Seattle caregivers regardless of the presence of patient depression. These differences were largest in the subscales regarding satisfaction with relationships and satisfaction with one's own performance as a caregiver, and were associated with a lower level of perceived social support. Since this data was collected prior to any treatment in both groups, we do not believe that treatments for the patient's depression could have played a role in these

findings. Due to the rapid industrialization of Korea over the last decades, we suspect that family-based support is not as great as it used to be in Korea. It is also possible that Korean families may have not yet developed support networks outside the family. This was evidenced by a low social support in Korean caregivers, which is in agreement with a previous study (Sung, 2001). According to Cattell's typology of support networks which was developed in a way to reflect networks, associated norms and values of residents including cultural issues (Cattell, 2001), it appears that the Korean social support network is in the transitional state. It is moving from either homogeneous or traditional network to the heterogeneous or solidarity models. The tie to the extended family for support has lost some of its essential features, yet informal or formal organization such as self help groups for the caregivers or daycare centers for the patients and caregivers offered by the community is just beginning to emerge (Hong et al., 2000; Yoon et al., 2000). The great need for support groups has also been reported (Park, Yu & Song, 1999). Since we do not have direct data about social networks in either the Seoul or Seattle group, we can only speculate about this transition in support.

Consistent with previous notions of an American culture that emphasizes individualism (Youn et al., 1999), caregivers in Seattle felt loss of time for self and loss of privacy more challenging than the caregivers in Seoul. This was evidenced by a relatively high score (3.8) on the item "have enough time for myself ". Although these caregivers' responses may have been due to the acute stage of the disease process, the concept of an independent and individualized self is congruent with Western European-American dominant culture (Landrine & Klonoff, 1992). Further, these findings were consistent with Youn and colleagues finding of the Korean and US caregiver's sense of burden in relation to traditional familism and independence in caring for persons with dementia (Youn et al., 1999).

Post-stroke fatigue (PoSF) has been reported to be a common sequela of stroke, occurring in 40–57% of the patients (Choi-Kwon, Han, Kwon & Kim, 2005; Choi-Kwon, Choi et al., 2006). It was interesting to note that the challenge of fatigue was reported only by Korean caregivers. One would not expect a cultural difference in either the incidence or challenge of fatigue. Rather the difference may reflect the different point at which the stroke survivors were in their recovery. The degree to which it poses challenging problems for informal caregivers indicates that this variable should be routinely recorded in studies of stroke recovery.

Seoul caregivers were more likely to report depressive symptoms above the score suggesting clinical depression than were their Seattle counterparts. It is possible that the high level of emotional distress may in fact be general among Koreans and not limited to caregivers. Previously, Choi-Kwon and colleagues have reported that Korean caregivers are often depressed and anxious and these were the factors influencing the caregiver burden (Choi-Kwon, Kim et al., 2005). Although the caregiver burden in stroke patients has not been studied cross culturally, a previous study of caregivers of elderly with dementia reported that the Korean and Korean-American caregivers had higher levels of burden, depression, anxiety than American Caucasians (Youn et al., 1999). Another cross-cultural study of caregivers of people with dementia also found depression was higher in Korean and Korean-american wives than in American Caucasian wives or daughters. (Lee & Farran, 2004) The absence of a non-caregiver comparison group in the current study, however, leaves open the possibility that results were due to general ethnic or cross national differences rather than to ethnicity and caregiving interactions. An alternative explanation might be the lack of social support available to Korean caregivers as compared to the counterparts in Seattle who perceived a higher level of social support. This is consistent with a previous finding that Korean caregivers expressed a lack of socio-emotional support and of social acknowledgement, which increased feelings of entrapment and depression (Chun, Knight & Youn, 2007). It is also possible that nursing homes and daycare centers for stroke patients are less available in Korea than in the US, and the Korean

caregivers may be depressed more often and have higher levels of burden (Choi-Kwon, Kim et al., 2005).

Our study has several limitations that should be considered in interpreting the findings. First, caregiver burden was assessed at different time points (Seoul averaging 14 months after stroke, Seattle within 4 months). We may thus have overestimated caregiver burden in the Seoul patient group since the data was collected during the chronic stages when the emotional burden may be high. Overestimation is less likely, however, since we previously reported that the mean overall burden score 3 years post stroke was 2.3 which was lower than that of the present study (Choi-Kwon, Kim et al., 2005). Furthermore, when we compared the SCQ means and sums on the Seattle group at the 4 month and 12 month follow ups, the Seattle caregivers were a little more burdened with respect to satisfaction with their own performance, but no statistical differences were found between two different follow ups (the data not shown).

Second, we excluded the patients who had severe communication problems and cognitive dysfunction. Since cognitive dysfunction and aphasia have been reported to be factors affecting caregiver burden (Thommessen, Wyller, Bautz-Holter & Laake, 2001), we might have underestimated the caregiver burden in all groups. We also have a small sample size from two urban populations that may not be generalizable to other regions of each country.

Thirdly, the interviews were carried out by the trained research nurses in each country with the use of structured questionnaires. Although the interviewing consistency was overseen by the project coordinator and principal investigator in each research group, unwanted bias may have been inadvertently introduced during the interview.

Finally, it is important to note that patients and caregivers in the Korean sample were classified as “depressed” on the basis of endorsing prominent depressive symptoms whereas diagnostic criteria for major depression were employed in addition to symptom ratings in the Seattle sample. It is possible that some patient participants in the Korean sample were classified as “depressed” whose depressive symptoms might not have qualified for a diagnosis of major depression using DSM-IV criteria. Thus, patients and caregivers from the Seattle sample who were classified as depressed might have had more intense or severe symptoms than subjects from Seoul sample. If this were true, the study findings indicating a higher level of caregiver burden in the Korean sample is even more impressive.

Conclusions

Despite the limitations of our study, it extends and confirms for stroke survivors’ informal caregivers what has been previously found in cross-cultural studies of caregiving in dementia. Caregiver burden is higher in the urban Korean caregiver group than in the urban US caregivers, particularly in the area of satisfaction with relationships, and probably related to lower perceived social supports.

Implication for practice

Rehabilitation nurses worldwide are increasingly becoming involved in supporting family caregivers in the community. These findings support the need for nurses and other health professionals to assess family caregiver burden, emotional status and available supports based on their own cultural background. The findings also suggest that strategies to assist caregivers should be developed differently for urban caregivers in the US and Korea. A prominent potential strategy for the Seattle group would be to assist caregivers to increase privacy and time for themselves. Whereas, for the Seoul caregivers, the data suggest a need for integrated extended family support systems to provide additional resources for the caregiver facing distress. Korean elderly persons could be supported by church and community organizations

and have more flexible support from kin. Although interventions for post-stroke depression are now being reported, there is relatively little work to assist caregivers in reducing their caregiver burden specifically related to depressed stroke survivors. The findings of our study suggest that cultural factors should be included in the design and application of such studies.

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References

- Bakas T, Austin JK, Okonkwo KF, Lewis RR, Chadwick L. Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing* 2002;34(5):242–251. [PubMed: 12391740]
- Brink TL. Screening tests for geriatric depression. *Clinical Gerontology* 1982;1:37–43.
- Brink TL. Proper scoring of the geriatric depression scale. *Journal of the American Geriatric Society* 1989;37(8):819–820.
- Cattell V. Poor people, poor places, and poor health: the mediating role of social networks and social capital. *Social Science & Medicine* 2001;52(10):1501–1516. [PubMed: 11314847]
- Choi-Kwon S, Choi JM, Kwon SU, Kang DW, Kim JS. Fluoxetine is not effective in the treatment of post-stroke fatigue: a double blind, placebo-controlled study. *Cerebrovascular Disease* 2006;23(2):103–108.
- Choi-Kwon S, Han SW, Kwon SU, Kang DW, Choi JM, Kim JS. Fluoxetine treatment in poststroke depression, emotional incontinence, and anger proneness: a double-blind, placebo-controlled study. *Stroke* 2006;37(1):156–161. [PubMed: 16306470]
- Choi-Kwon S, Han SW, Kwon SU, Kim JS. Poststroke fatigue: characteristics and related factors. *Cerebrovascular Disease* 2005;19(2):84–90.
- Choi-Kwon S, Kim HS, Kwon SU, Kim JS. Factors affecting the burden on caregivers of stroke survivors in South Korea. *Archives of Physical Medicine & Rehabilitation* 2005;86(5):1043–1048. [PubMed: 15895355]
- Chun M, Knight BG, Youn G. Differences in stress and coping models of emotional distress among Korean, Korean-American and White-American caregivers. *Aging & Mental Health* 2007;11(1):20–29. [PubMed: 17164154]
- Clark PC. Commentary. *Rehabilitation Nursing* 2006;31(4):173.
- Clark PC, Dunbar SB, Aycock DM, Courtney E, Wolf SL. Caregiver perspectives of memory and behavior changes in stroke survivors. *Rehabilitation Nursing* 2006;31(1):26–32. [PubMed: 16422042]
- Egbert N, Koch L, Coeling H, Ayers D. The role of social support in the family and community integration of right-hemisphere stroke survivors. *Health Communication* 2006;20(1):45–55. [PubMed: 16813488]
- Freedland KE, Skala JA, Carney RM, Raczynski JM, Taylor CB, Mendes De Leon CF, et al. The Depression Interview and Structured Hamilton (DISH): Rationale, Development, Characteristics, and Clinical Validity. *Psychosomatic Medicine* 2002;64(6):897–905. [PubMed: 12461195]
- Glass TA, Matchar DB, Belyea M, Feussner JR. Impact of social support on outcome in first stroke. *Stroke* 1993;24(1):64–70. [PubMed: 8418553]
- Grant JS, Bartolucci AA, Elliot TR, Giger JN. Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Injury* 2000;14(12):1089–1100. [PubMed: 11147581]
- Han B, Haley WE. Family caregiving for patients with stroke. Review and analysis. *Stroke* 1999;30(7):1478–1485. [PubMed: 10390326]

- Hong YS, Suh MJ, Kim KS, Kim IJ, Cho NO, Choi HJ, et al. Relations between perceived burden and social support of stroke patient's family caregiver. *Journal of Nurses Academic Society (Taehan Kanho Hakhoe Chi)* 2000;30(3):595–605. [article in Korean].
- Landrine H, Klonoff EA. Culture and health-related schemas: a review and proposal for interdisciplinary integration. *Health Psychology* 1992;11(4):267–276. [PubMed: 1396496]
- Lee EE, Farran CJ. Depression among Korean, Korean American, and Caucasian American family caregivers. *Journal of Transcultural Nursing* 2004;15(1):18–25. [PubMed: 14768412]
- Mant J, Winner S, Roche J, Wade DT. Family support for stroke: one year follow up of a randomised controlled trial. *Journal of Neurology, Neurosurgery and Psychiatry* 2005;76(7):1006–1008.
- McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke* 2005;36(10):2181–2186. [PubMed: 16151029]
- Mitchell PH, Powell L, Blumenthal J, Norton J, Ironson G, Pitula CR, et al. A short social support measure for patients recovering from myocardial infarction: the ENRICHD Social Support Inventory. *Journal of Cardiopulmonary Rehabilitation* 2003;23(6):398–403.
- Morimoto T, Schreiner AS, Asano H. Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age and Aging* 2003;32(2):218–223.
- Park YH, Yu SJ, Song MS. Caregiver Burden of Families with Stroke Patients and their Needs for Support Group Intervention. *Journal of Korean Academic Society of Adult Nursing, (Sungin Kanho Hakhoe Chi)* 1999;11(1):119–134. [article in Korean].
- Pierce LL, Steiner V, Hicks B, Holzaepfel AL. Problems of new caregivers of persons with stroke. *Rehabilitation Nursing* 2006;31(4):166–172. [PubMed: 16789675]
- Scholte op Reimer WJM, de Haan RJ, Pijnenborg JM, Limburg M, van den Bos GAM. Assessment of burden in partners of stroke patients with the sense of competence questionnaire. *Stroke* 1998;29(2):373–379. [PubMed: 9472877]
- Scholte op Reimer WJM, de Haan RJ, Rijnders PT, Limburg M, van den Bos GAM. The Burden of Caregiving in Partners of Long-Term Stroke Survivors. *Stroke* 1998;29 (8):1605–1611. [PubMed: 9707201]
- Sit JW, Wong TK, Clinton M, Li LS, Fong YM. Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of Clinical Nursing* 2004;13(7):816–824. [PubMed: 15361155]
- Sung KT. Family support for the elderly in Korea: continuity, change, future directions, and cross-cultural concerns. *Journal of Aging & Social Policy* 2001;12(4):65–79. [PubMed: 11799915]
- Thommessen B, Wyller TB, Bautz-Holter E, Laake K. Acute phase predictors of subsequent psychosocial burden in carers of elderly stroke patients. *Cerebrovascular Disease* 2001;11(3):201–206.
- Tooth L, McKenna K, Barnett A, Prescott C, Murphy S. Caregiver burden, time spent caring and health status in the first 12 months following stroke. *Brain Injury* 2005;19(12):963–974. [PubMed: 16263639]
- van Exel NJ, Koopmanschap MA, van den Berg B, Brouwer WB, van den Bos GA. Burden of informal caregiving for Stroke Patients. Identification of caregivers at risk of adverse health effects. *Cerebrovascular Diseases* 2005;19(1):11–17. [PubMed: 15528879]
- Visser-Meily JM, Post MW, Riphagen II, Lindeman E. Measures used to assess burden among caregivers of stroke patients: a review. *Clinical Rehabilitation* 2004;18(6):601–623. [PubMed: 15473113]
- Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey M, et al. Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research* 1982;17 (1):37–49. [PubMed: 7183759]
- Yoon H, Cha H, Cho S. The impact of social support on the family caregivers' burden and depression. *Journal of the Korea Gerontological Society (Hankook noyeon Hak)* 2000;20(1):1–19. [article in Korean].
- Youn G, Knight BG, Jeong HS, Benton D. Differences in familism values and caregiving outcomes among Korean, Korean American, and White American dementia caregivers. *Psychology & Aging* 1999;14(3):355–364. [PubMed: 10509692]
- Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica* 1983;67(6):361–370. [PubMed: 6880820]

Table 1

Characteristics of Stroke Survivors in Seoul (Korean) and Seattle (U.S).

Variable (mean, standard deviation or percent)	Seoul Not Depressed N = 29	Seoul Depressed N = 12	Seattle Depressed N = 33
Age mean years (s.d.)	58.6 (8.3)	61.8 (8.95)	58.4 (13.4)
Less than 62	19(65.5 %)	7(58.3 %)	20 (60.6%)
62 or older	10(34.5 %)	5(41.7 %)	13 (39.4%)
Sex – Male	24(82.8 %)	10(83.3 %)	22 (66.7%)
Female	5(17.2 %)	2(16.7 %)	11 (33.3%)
Education Mean yrs (s.d.)	11.2 (4.6)	9.5 (3.1)	12.9 (2.3)
≥12 years	17(58.6%)	5(38.5%)	32 (97.0 %)
< 12 years	12(41.4%)	7(61.5%)	1 (3.0 %)
Marital Status			
Married/Partnered	28(96.6%)	12(100%)	22 (66.6%)
Single/widowed/divorced	1(3.4%)	0(0%)	11 (33.4%)
Employment status Employed	15(51.7)	3(25%)	5 (15.1%)
Unemployed/retired/other	14(48.3)	9(75%)	28 (84.9%)
Hypertension – Yes	24(82.8)	9(75%)	30 (91.9%)
No	5(17.2%)	3(25%)	3 (9.1%)
Diabetes - Yes	10(34.5%)	2(16.7%)	17 (51.5%)
No	19(65.5%)	10(83.3%)	16 (48.5%)
Barthel Index mean	97.8 (7.8)	96.7 (6.2)	75.9(26.7)
Dysarthria – Yes	15(51.7%)	8(66.7%)	13 (39.4%)
No	14(48.3%)	4(33.3%)	20 (60.6%)

Table 2

Caregiver Characteristics in Seoul (Korean) and Seattle (U.S.) Samples.

Characteristic (means, standard deviation or percent)	Seoul Not Depressed Patient N=29	Seoul Depressed Patient N=12	Seattle Depressed Patient N=33
Age – mean years (s.d.)	58.6 (8.3)	61.8 (8.95)	52.4 (13.6)
Sex – male	2(6.9%)	2(16.7%)	13 (39.4%)
Female	27(93.1%)	10(83.3%)	20 (60.6%)
Education			
<12 th grade	10(34.5%)	8(66.7%)	4 (12.9%)
12 th grade	11(37.9%)	2(16.7%)	14 (45.2 %)
Some college, bachelor degree or more	8(27.6%)	1(8.3%)	13 (41.9%)
Employment			
Employed	23(79.3%)	5(41.7%)	16 (48.5%)
Unemployed	6(20.7%)	7(58.3%)	17 (51.5%)
Hours of care per day			
15 hours or more	4(13.8%)	2(16.7%)	7 (23.3%)
< 15 hours	25(86.2%)	10(83.3%)	26 (76.7%)
Caregiving Help - Yes	3(10.3%)	2(16.7%)	10 (31%)
No	26(89.7%)	10(83.3%)	23 (69%)
Relationship to Patient			
Spouse	27(93.1%)	11(91.7%)	21 (63.6%)
Son or Daughter	1(3.4%)	1(8.3%)	5 (15.2%)
Daughter-in-law	1(3.4%)	0(0%)	1 (3.0%)
Other	0	0	6 (18.2%)
Own health before patient stroke			
Good/VG/Excellent	16(55.2%)	8(66.7%)	21 (75.0%)
Average/Fair	10(34.5%)	1(8.3%)	6 (21.4%)
Poor	3(10.3%)	3(25%)	1 (3.6%)
Own health (current status)			
Good/Excellent	13(44.8)	6(50%)	19 (65.5%)
Average/Fair	5(17.2%)	1(8.3%)	7 (24.1%)

Characteristic (means, standard deviation or percent)	Seoul Not Depressed Patient N=29	Seoul Depressed Patient N=12	Seattle Depressed Patient N=33
Poor	11(37.9%)	5(41.7%)	3 (10.3%)
Depression(caregiver) Yes	15(51.7%)	7(58.3%)	12 (36.4%)
No	14(48.3%)	5(41.7%)	21 (63.6%)
Caregiver social support-ESSI mean sum	19.7 (4.0)	17.3 (4.9)	21.6(10.8)
Burden Score (SCQ overall mean)	2.5 (0.6)	2.8 (0.4)	2.3 (0.4)

Table 3

Sense of Caring Competence (Burden) Item and Subscale Comparisons.

Subscale or Item (means, standard deviation; means range from 1 to 4, higher score = greater burden)	Seoul Depressed Patients N=12	Seoul Not Depressed Patients N=29	Seattle Depressed Patients N = 33
Overall Mean (s, d)	2.8 (0.4)	2.5 (0.6)	2.3 (0.4)
Satisfaction with relationship with recipient of care (Subscale 1: 7 items)	2.6 (0.8)	2.6 (0.8)	1.9 (0.5)
Satisfaction with own performance as caregiver (Subscale 2: 12 items)	2.7 (0.3)	2.4 (0.7)	2.2 (0.5)
Consequences of involvement in care for personal life of caregiver (Subscale 3: 8 items)	3.0 (0.7)	2.6 (0.7)	2.7 (0.5)
Individual Items – SCQ			
1. Responsibility weighs heavily	3.4(1.0)	3.1(1.1)	2.97 (0.9)
2. Care needs are clear	1.7(1.0)	2.1(1.2)	2.3 (1.4)
3. Feel Capable to care for	1.7(0.8)	1.9(1.0)	2.5(1.4)
4. Do less than could/should at present	3.3(1.2)	2.2(1.4)	2.24 (0.9)
5. Feel Angry about interactions	3.0(1.3)	2.8(1.4)	1.8 (0.73)
6. Do less than could/should in past	2.9(1.3)	2.2(1.4)	2.2 (0.9)
7. Feel guilty about interaction	2.7(1.5)	1.9(1.2)	1.8 (0.9)
8. Embarrassed over X's behavior	3.3(1.2)	2.9(1.3)	1.6 (0.8)
9. Feel nervous or depressed	3.4(1.1)	3.2(1.3)	1.6 (0.7)
10. X appreciates my care	2.1(1.1)	2.8(1.3)	2.7 (1.5)
11. Care benefits X	1.9(1.2)	1.5(0.6)	2.97 (1.4)
12. Cannot leave alone	3.7(0.8)	2.8(1.3)	2.3 (.80)
13. Worry all the time	4.0(0.0)	3.9(0.4)	2.7 (0.9)
14. Requests over and above needs	2.6(1.5)	2.2(1.3)	2.2 (0.8)
15. Have Enough time for myself	2.5(1.4)	2.1(1.3)	3.5 (0.7)
16. Feel resentful	2.7(1.4)	2.3(1.4)	1.67 (.65)
17. Not pleased with own performance	3.8(0.6)	3.6(0.7)	3.1 (1.3)
18. Feel useful	1.4(0.7)	1.3(0.5)	2.5 (1.4)
19. Feel strained	3.4(1.1)	3.2(1.2)	2.15 (0.9)
20. My health has suffered	3.3(1.2)	2.5(1.4)	1.88 (0.9)
21. As much privacy as I need	1.5(1.2)	1.7(1.0)	3.4 (0.9)

Subscale or Item (means, standard deviation; means range from 1 to 4, higher score = greater burden)	Seoul Depressed Patients N=12	Seoul Not Depressed Patients N=29	Seattle Depressed Patients N = 33
22. My social life suffered	2.5(1.6)	2.0(1.3)	2.3 (.99)
23. Wish for better relationship	3.1(1.2)	3.0(1.2)	2.4 (.9)
24. X expects care only from me	3.4(0.9)	3.1(1.3)	2.3 (.95)
25. X behaves to have own way	3.6(1.0)	3.3(1.2)	2.2 (.95)
26. X behaves to annoy me	2.4(1.5)	2.2(1.3)	1.6 (0.8)
27. X behaves to manipulate me	1.8(1.1)	2.5(1.4)	1.6 (0.8)

Table 4
Most Challenging Things in Caring for Stroke Survivors – Seoul (Korean) and Seattle (U.S.) Samples.

Most Challenging Things	Korean Depressed Pt	Korean Not Depressed Pt	Seattle Depressed Pt
None	2(12.50%)	13(43.33%)	12 (36%)
Fatigue	2(12.50%)	5(16.67%)	0
Worry about the patient illness	3(18.75%)	5(16.67%)	0
Economical burden	3(18.75%)	2(6.67%)	1 (3%)
Anger of the patients	5(31.25%)	2(6.67%)	0
Non-compliance to smoking and drinking	0(0%)	2(6.67%)	0
Preparing for new diet (low salt food, diabetic)	0(0%)	1(3.33%)	1 (3%)
Hopelessness	1(3.33%)	0(0%)	0
Not having enough time, patience with slowness			4 (12%)
Dealing with moods, motivation			7 (21%)
Communication			2 (6%)
Generally stressful			2 (6%)