

Psychosocial Responses and Quality of Life among Amyotrophic Lateral Sclerosis Patients and Their Caregivers*

Oh, Hyunjin¹

¹Part-time Lecturer, Department of Nursing, Daejeon University

Purpose: The purpose of this study was to explore the psychosocial responses and quality of life (QOL) among Amyotrophic Lateral Sclerosis (ALS) patients and their caregivers in South Korea. **Methods:** A cross-sectional design was used. Purposive sample of 15 ALS patients and their 14 caregivers were recruited via Korean Amyotrophic Lateral Sclerosis Association (KALSA) website. Demographic characteristics, hopelessness, quality of life, physical function, and caregiver burden were measured. **Results:** The mean period after being diagnosed with ALS was 57.73 months. The mean score of amyotrophic lateral sclerosis functional rating scale and quality of life was 21.33 (SD=11.97) and 5.70 (SD=1.23) respectively. The mean score of hopelessness was 11.87 (SD=4.72). The caregivers' mean score of McGill quality of life was 4.29 (SD=1.46), and the mean score of McGill quality of life-single item scale was 4.29 (SD=2.02). **Conclusion:** Since the cause of ALS has not been identified and cure is yet to be discovered, supportive care should be provided for not only quality of life but hope of patients. The findings may be used to develop knowledge based nursing intervention for patients diagnosed with ALS and their caregivers.

Key words : Amyotrophic lateral sclerosis, Quality of life, Caregivers

INTRODUCTION

Background and Significance

Amyotrophic lateral sclerosis (ALS) is a progressive and degenerative neuromuscular disease that affects primarily motor neurons (Charles & Swash, 2001). Motor neuron degeneration results in progressive muscle weakness and atrophy throughout the body. However, cognitive functions, such as those governing intelligence and personality, are fairly maintained (Carvalho, Schwartz, & Swash, 1995).

Besides the devastating physical symptoms, patients often experience depression, anxiety, suffering, and hopelessness

(Ganzini et al., 1999; Rabkin et al., 2000) related to the destructive characteristics of the disease. Studies have shown that ALS patients report frequent depressive symptoms, but the prevalence of diagnosed depression is relatively low. The incidence of major depression based on the DSM-IV was 11% out of 100 ALS patients (Ganzini et al., 1998), while Rabkin et al. (2000) found out that only 2% showed major depression. Oh et al. (in press) examined the degree of functional impairment and depressive symptoms in patients with ALS in Korea, as well as the relationship between functional impairment and depressive symptoms. The study reported high functional impairment and a high level of depressive symptoms among the participants, and a

주요어 : 근위축성 측삭경화증, 삶의 질, 간호자

* This paper is a part of PhD dissertation at University of Washington.

Address reprint requests to : Oh, Hyunjin

Department of Nursing, Daejeon University, 96-3 Youngun-dong, Dong-gu, Daejeon 300-716, Korea

Tel: 82-10-3056-6964 Fax: 82-42-280-2785 E-mail: hyunjino@gmail.com

투고일: 2011년 10월 1일 수정일: 2011년 11월 2일 게재확정일: 2011년 11월 21일

greater functional impairment in association with greater depression.

Hopelessness might be related to suicidal thoughts and intentions in ALS patients. Ganzini et al. (1998) claimed that hopelessness is more often related to the considering of assisted suicide than depression. In their study, many patients with depressive symptoms showed hopelessness, but patients with hopelessness expressed no depression.

Much research on quality of life (QOL) in ALS patients has been conducted in the medical field and a number of studies clearly state that QOL in ALS patients is not determined by their physical function and strength alone (Neudert et al., 2004; Robbins et al., 2001; Simmons et al., 2000). Previous studies show that psychological, existential, or spiritual factors rather than physical functions in terminally ill patients take a more significant role in maintaining their QOL (Ferrell et al., 1992). Although patients receive complicated and comprehensive medical care for serious illness, family members typically provide informal care for them. Care and assistance provided by family members are an important part of patient care, and physical and emotional burden may be placed on them.

A study describes five possible burdens of family caregiving for seriously ill patients; 'time and logistics, physical tasks, financial costs, emotional burdens and mental health risks, and physical health risks' (Rabow, Hauser, & Adams, 2004). Patient caregiving requires devoted time and administrative details such as coordinating medications, treatments, and social services. Physically laborious work can occur when family members take care of elderly or disabled patients. Family caregivers also experience financial burden including absolute expenses for medical care, lost income and benefits. Emotional burden and health risks for caregivers are also expected in caregiving.

As a progressive disease, ALS requires increasing levels of physical assistance for patients from caregivers (Chio, Gauthier, Calvo, Ghiglione, & Mutani, 2005). The emotional burden that family members experience is closely related to the patient's disability and disease duration. In addition, an ALS caregiver's psychological distress, such as mood, burden, and strain, is significantly increased over time (Goldstein, Atkins, Landau, Brown, & Leigh, 2006). Financial costs for caring for ALS patients are huge. Expenses for a mechanical ventilator are about \$200,000 a year in U.S. dollars, and costs for the

medication riluzole average about \$550 per month (Mitsumoto & Rabkin, 2007) in the U.S. Generally, caregiving of ALS patients has been described as burdensome and stressful for family caregivers.

It is estimated that approximately 1,300 people were affected by ALS in South Korea in 2005 (Kim, 2006), but there has been little research on the incidence or ALS disease characteristics in Korea. A few research articles explored the level of physical function, depression of ALS patients, and family caregiver burden (Oh et al., in press; Paek, 2005; Park et al., 2006); there is little focus on psychosocial responses and QOL in the body of knowledge.

Purpose of Study

The purpose of this study was to explore the psychosocial responses and QOL of ALS patients and their caregivers.

Specific aims were as follows:

- To describe demographic characteristics, functional impairments, QOL, and hopelessness from ALS patients
- To describe demographic characteristics, QOL, and hopelessness, and caregiver burden from the primary caregiver of ALS patients

METHODS

Design

A cross-sectional design was used to assess psychosocial responses and QOL among ALS patients and their caregivers in South Korea. The original project used a qualitative ethnographic approach with a mixed method to explore illness experiences and describe psychological responses and QOL of ALS patients and their caregivers. The written consent form included the purpose of the study, the procedure being followed, benefits and potential risks, rules of confidentiality, and an explanation of the participants' rights to withdraw and to refuse response. Verbal explanation of this information was also provided before interested parties read the written consent form. Participants were asked to read the form and ask questions. Human subjects approval for this study was obtained from the Institutional Review Board at University of Washington (#36482).

Setting and Samples

The original study was conducted from September 2009 to July 2010 in a metropolitan area near Seoul, Korea. Purposive convenience sample of 15 ALS patients and their 14 caregivers were recruited via Korean Amyotrophic Lateral Sclerosis Association (KALSA) website. Since ALS is a rare and incurable disease, the access to ALS population is limited. KALSA has patient registry system to serve ALS patients and their families. Diverse clinical stages of patients were involved. The inclusion criteria for patients were individuals who: (a) received a confirmed ALS diagnosis by a physician; (b) were registered with the KALSA; (c) were able to communicate either verbally or nonverbally; (d) were over 18 years of age and understand the purpose of the study; (e) lived in metropolitan area near Seoul and Daejeon, due to the accessibility and feasibility of participants. The inclusion criteria for primary caregivers were individuals who: (a) took main responsibility for patient care; (b) were identified as his/her primary caregiver by the patient; (c) were over 18 years of age; and (d) understood the purpose of the study. A patient or a caregiver with a history of other neurologic conditions that affect cognition (e.g., stroke, traumatic brain injury) or serious mental illness (e.g., schizophrenia, major depression) were excluded from this study.

Measures

Four instruments were used to measure patient characteristics, functional level, QOL, and hopelessness: (a) the demographic questionnaire; (b) the Korean version of the Amyotrophic Lateral Sclerosis Specific Quality of Life Scale (K-ALSSQOL); (c) the Korean version of the Amyotrophic Lateral Sclerosis Functional Rating Scale -Revised (K-ALSFRS-R); (d) the Korean version of Beck Hopelessness Scale (K-BHS). Four instruments - the demographics, Caregiver Burden, McGill QOL Scale (MQOL), and the K-BHS - were used to measure caregiver characteristics, QOL, burden, and hopelessness. Patients who had functional limitations received assistance from the researcher. The length of time for completing the packet ranged from 20 to 40 minutes.

● Demographic questionnaire

The demographic questionnaire was created for this study to

acquire demographic and background information for each participant. Patient participants were asked disease-specific demographic questions related to such items as symptoms, diagnosis, and periods of illness experiences.

● Functional Level of ALS Patients

Korean version of the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (K-ALSFRS-R) was used. The ALSFRS-R is a 12-item self-report Likert scale (0: worst function to 4: best function) designed to assess the functional status of patients with ALS (Cedarbaum et al., 1999). For example, in the speech domain, “4 for normal speech processes, 3 for detectable speech disturbance, 2 for intelligible with repeating, 1 for speech combined with nonvocal communication, and 0 for loss of useful speech.” The ALSFRS-R measures speech, arm use, walking and breathing functions (Cedarbaum & Stambler, 1997; Cedarbaum, et al., 1999; Gordon, Miller, & Moore, 2004). The ALSFRS is a useful tool to evaluate activities of daily living (ADLs) of patients with ALS and is easy to administer for patients (The ALS CNTF treatment study phase I-II Study Group, 1996). The total score ranges from 0-48, and the ALSFRS-R was tested for reliability with a Cronbach alpha of .73 (Cedarbaum et al., 1999). The Korean version of the ALSFRS-R was translated into Korean by Kim, et al. (2007) with Cronbach's alpha was .87 and test-retest reliability was .99 (Kim et al., 2007). The validity of the K-ALSFRS-R was also evaluated with the Norris scale and the Apple ALS rating scale (Kim et al., 2007). Chronbach's alpha of K-ALSFRS-R was .91 in this study.

● Quality of life for ALS Patients

The Korean version of the Amyotrophic Lateral Sclerosis Specific Quality of Life Scale (K-ALSSQOL) was used. The ALSSQOL is a self-report questionnaire with 59-items to measure the concept of quality of life for ALS patients (Simmons et al., 2006). The ALSSQOL includes six dimensions: (a) negative emotion (13 items); (b) interaction with people and the environment (11 items); (c) intimacy (7 items); (d) religiosity (4 items) (e) physical symptoms (6 items); and (f) bulbar function (5 items). This questionnaire uses a 10-point Likert-type scale ranged from 0 (least desirable situation) to 10 (most desirable). Six different types of response format was used to measure the degree of QOL

experienced last week: very bad to excellent, not at all to extremely, no problem to tremendous problem, strongly disagree to strongly agree, not at all to very much, and never to very often. These questions followed the format of, "Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past week, the quality of my life has been..." The ALSSQOL was translated into Korean and back-translated by the author and two bilingual Korean translators who are culturally immersed in both American and Korean culture. In the original study, the internal consistency was assessed by the coefficient alpha ranged from .75 to .91 which was acceptable (Simmons et al., 2006). The ALSSQOL demonstrated concurrent, convergent, and discriminant validity for the overall instrument (Simmons, et al., 2006). Chronbach's alpha was .84 in this study.

- Quality of life for the Caregivers

Korean version of the McGill QOL Questionnaire (MQOL-K) was used. The MQOL developed by Cohen and colleagues (1995) to measure the comprehensive QOL is a self-report measure of 16 items on a 7-point Likert-type scale ranged from 1 (Strongly disagree) to 7 (Strongly agree). This scale was used to measure the degree of QOL experience during the past week consistent to the other scales, so that "two days" was changed to "last week". The MQOL includes the five dimensions of physical symptoms, physical well-being, psychological well-being, existential well-being, and support. Reliability and validity of the MQOL-K were verified with Cronbach's alphas ranged from .62 to .90 (Kim et al., 2007). Convergent validity and a good concurrent validity with the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 were established (Kim et al., 2007). Chronbach's alpha was .75 in this study.

- Hopelessness

Korean version of the Beck Hopelessness Scale (BHS) was used. The BHS assesses the general inclination in the participants toward pessimism and negative expectancies about the present and future (Beck, Weissman, Lester, & Trexler, 1974). The BHS is a 20-item self-report with true-false statement designed to assess the positive and negative belief about the future an individual perceived during the past week.

Three dimensions of hopelessness were covered: affective (feelings about the future), motivational (loss of motivation),

and cognitive (lack of future expectations) (Beck et al., 1974). Participants were asked to describe their recent experiences over the past week, which is comparable to ALSSQOL questionnaires. The range of the total scores of the BHS is between 0-20. Beck et al. (1974) reported the BHS reliability coefficient as .93, and concurrent validity was tested. The Korean version of BHS was translated by Shin et al. (1990), and Cronbach's alpha of the K-BHS was .83 (Shin et al., 1990). Chronbach's alphas were .85 for patients and .80 for caregivers in the present study.

- Caregiver Burden

Caregiver Burden developed by Korean researchers (Suh & Oh, 1993) is a 25-item scale designed to measure caregiver burden for Korean people. It is composed of five dimensions including physical, emotional, social, financial burden, and dependency. Scores vary from 25 to 125, with a higher score implying greater burden on caregivers. The Cronbach's alpha for internal consistency was .89, and content validity was tested in their study (Suh & Oh, 1993). A sample question is, "I feel depressed when I take care of a patient." Chronbach's alpha in this study was .82.

Data Analysis

The Statistical Package for the Social Sciences (SPSS) 17.0 version was used for data analysis. Descriptive statistics, including mean, median, and standard deviation (SD), were obtained to describe the sociodemographic, disease-specific variables, functional level, QOL, hopelessness, and caregiver burden for ALS patients and their caregivers.

RESULTS

Description of ALS Patients

The 15 patients had a mean age of 49.2 years (range 38-64). They were 86.7% male (n=13); 93.3% were married (n=14), 53.3% were high school graduates (n=8), and 93.3% were unemployed at the time of the study (n=14). The total family income ranged from less than 1,000,000 won to over 4,000,000 won per month, and 53.3% reported an income of less than 1,000,000 won per month. Eighty percent (n=12) received care from their wives. One adult son, one husband,

and one mother were identified as the primary caregiver. About 46.6% of patients (n=7) reported their perceived health as “very good” and “good.” Approximately, 66.7% had regular visits to hospitals (n=10), and five patients who did not have regular hospital

Table 1. ALS Patient Demographics (N=15)

| Characteristic | Mean ±SD/n (%) |
|----------------------------|--|
| Age (years) | 49.2±7.21 (38-64) |
| Gender-male | 13 (86.7) |
| Marriage | 14 (93.3) |
| Education | Middle school 1 (6.7) High school 8 (53.3) College 6 (40.0) |
| Employment | Currently employed 1 (6.7) Currently unemployed 14 (93.3) |
| Monthly income (1,000 won) | <1,000 8 (53.3) 1,000-2,000 4 (26.7) 3,000-4,000 1 (6.7) >4,000 2 (13.3) |
| Primary caregiver | Wife 12 (80.0) Husband 1 (6.7) Son 1 (6.7) Mother 1 (6.7) |
| Perceived health status | Very good 2 (13.3) Good 5 (33.3) Bad 4 (26.7) Very bad 4 (26.7) |
| Regular visit to hospital | Yes 10 (66.7) No 5 (33.3) |
| If no, why (n=5) | Not helpful 2 (40.0) Physical disability 1 (20.0) Transportation 2 (40.0) |

Table 2. Disease Specific Characteristics of ALS Patients (N=15)

| Characteristic | Mean ±SD/n (%) |
|--|--|
| Length of illness (month-diagnosis to study entry) | 57.73±39.29 (15-130) |
| Familial ALS | 1 (6.7) |
| Early symptom | Weakness in upper 6 (40.0) Weakness in lower 6 (40.0) Dysarthria 1 (6.7) Others 2 (13.3) |
| Gastrostomy | Yes 3 (20.0) No 12 (80.0) |
| Intake of rilutek | Taking now 4 (26.7) Took before, not now 10 (66.7) Never taken 1 (6.7) |
| CAM experience | Yes 14 (93.3) No 1 (6.7) |
| BiPap/Ventilator | Yes 6 (40.0) No 9 (60.0) |
| Nasal ventilator | Yes 3 (20.0) |

Table 3. Function, QOL, Hopelessness for ALS Patients (N=15)

| Instruments | Mean ±SD |
|-------------|-------------|
| ALSFRS | 21.33±11.97 |
| ALSSQOL | 5.70± 1.23 |
| MQoL-SIS | 4.93± 3.13 |
| BHS | 11.87± 4.72 |

ALSFRS=Amyotrophic Lateral Sclerosis Functional Rating Scale; ALSSQOL=Amyotrophic Lateral Sclerosis Specific Quality of Life; MQoL-SIS=McGill Quality of Life-Single Item Scale; BHS=Beck Hopelessness Scale.

visits defined the reasons as “not helpful (n=2), physical difficulty (n=1), and difficulties in transportation (n=2).”

The mean time since ALS diagnosis was 57.73 months, with a range of 15 months to 130 months. One participant reported a diagnosis of the familial type of ALS. Approximately 80% experienced weakness in upper and lower extremities as their early symptoms (n=12). Eighty percent (n=12) did not have gastrostomy, and only 26.7% (n=4) were currently taking Rilutek. About 93% (n=14) had experiences with complementary alternative medicine such as acupuncture, moxibustion, and herbal medicine. Six participants (40.0%) used home ventilators or BiPAP to support respiration, and three of them used nasal ventilators.

As depicted in Table 3, the mean score of ALSFRS was 21.33 (SD=11.97). ALSFRS total scores of participants showed that patients at various stages of ALS, ranging from mildly

Table 4. Demographics of ALS caregivers (N=14)

| Characteristic | Mean ±SD/n (%) |
|----------------------------|--|
| Age (years) | 47.79±9.50 (24-64) |
| Gender-female | 12 (85.7) |
| Married | 13 (92.9) |
| Education | Elementary school 1 (7.1) Middle school 2 (14.3) High school 7 (50.0) College 4 (28.6) |
| Employment | Currently employed 5 (35.7) Currently unemployed 9 (64.3) |
| Monthly income (1,000 won) | <1,000 6 (42.9) 1,000-2,000 4 (28.6) 3,000-4,000 2 (14.3) >4,000 2 (14.3) |
| Perceived health status | Very good 1 (7.1) Good 6 (42.9) Bad 5 (35.7) Very bad 2 (14.3) |
| Caregiving hours/day | 15.93±8.26 (1-24) |

affected by the disease to severely affected. The mean duration of ALS was over 4.8 years, and there was large variation in illness duration. The mean ALSSQOL score was 5.70 (SD=1.23). Each item of the ALSSQOL was scored on a 0 to 10 scale, with 0 the least desirable situation and 10 the most desirable. The mean MQoL-SIS for general QOL was 4.93 (SD=3.13). Using the Korean version of BHS, the mean score of hopelessness was 11.87 (SD=4.72) indicating that as a group of the ALS patients in this study experienced moderate level of hopelessness.

Description of ALS Caregivers

The 14 caregivers had a mean age of 47.79 years (range 24-64). They were 85.7% female (n=12); 92.9% were married (n=13), 50% were high school graduates (n=7), and 64.3% were unemployed (n=9). The total family income ranged from less than 1,000,000 won to 4,000,000 won per month, and 42.9% reported an income of less than 1,000,000 won per month. About 42.9% of caregivers (n=6) reported their perceived health as "good," and 35.7% as "bad." Average hours of caregiving per day was 15.93, with a range from 1 to 24 hours.

The caregivers' mean MQoL score was 4.29 (SD=1.46), and the mean MQoL-SIS score was 4.29 (SD=2.02). The MQoL subscales scores are shown in Table 5; the mean physical symptoms was the lowest (mean=3.14), indicating lowest domain of MQoL, and support domain was the highest (mean=5.14). The mean score of hopelessness was 7.21 (SD=3.93), indicating that, as a group, the caregivers in this study experienced a mild level of hopelessness. The mean

Table 5. McGill QOL, Hopelessness, Caregiver Burden for ALS Caregivers (N=14)

| Instruments | Mean ±SD (range) |
|-------------------------|-----------------------|
| McGill QOL | 4.29±1.46 (0.31-5.85) |
| Physical (items 1-4) | 3.14±1.31 (0-5) |
| Psychological(item 5-8) | 3.64±1.46 (0-6) |
| Existential(items 9-14) | 5.08±2.08 (0-8.33) |
| Support(items 15,16) | 5.14±1.76 (1.50-7.50) |
| MQoL-SIS | 4.29±2.02 (0-7) |
| BHS | 7.21±3.93 (3-19) |
| Caregiver burden | 3.13±0.47 (2.56-3.96) |
| Physical CB | 3.48±0.76 (2.67-5.00) |
| Financial CB | 3.00±0.64 (1.67-3.67) |
| Social CB | 3.88±0.76 (2.50-5.00) |
| Dependency CB | 2.73±0.70 (1.67-3.83) |
| Emotional CB | 3.00±0.43 (2.33-3.89) |

MQoL-SIS=McGill Quality of Life-Single Item Scale;

BHS=Beck Hopelessness Scale.

caregiver burden was 3.13 (SD=0.47). Caregivers reported the most burden in the physical domain and least in the dependency domain.

DISCUSSION

This is the first study measuring various psychosocial responses and QOL for ALS patients and their caregivers in Korea. QOLs in ALS patients and their caregivers were evaluated, using an ALS-specific quality of life scale for patients and the McGill quality of life scale for caregivers. In this study, both patients and caregivers rated low quality of life. The mean ALS-specific QOL score was 5.70 (SD=1.23), and the McGill QOL score was 4.29 (SD=1.46). The McGill QOL single-item scale for both patients and caregivers was reported at 4.93 for patients and 4.29 for caregivers. This result show the quality of life for the ALS population in South Korea is severely deteriorated.

The ALS-specific QOL score was relatively (M=5.70, SD=1.23) low compared to other Western studies. For example, the mean ALS-specific quality of life score was 7.1 in one study (Simmons et al., 2006). Since the ALS-specific quality of life scale was developed from the McGill QOL scale and also ranged from 0 to 10, relative comparison is possible between the two scales. Another study measuring QOL with the use of the McGill QOL Scale reported 6.8 (Gauthier et al., 2007). Study participants in both Simmons (2006) and Gauthier (2007) showed lower functional impairments, presenting higher functional rating scale scores (27.0 and 28.7, respectively).

The mean ALS functional rating score was 21.33 in this study, meaning that patient participants in this study experienced higher functional impairment than those of Simmons, et al. (2006) and Gauthier et al. (2007). In addition, the mean length of illness was about 37 months and 36 months respectively (Gauthier et al., 2007; Simmons et al., 2006). The mean illness period in this study was about 57 months, presenting that participants in this study experienced ALS longer than others in Western studies. Although participants in the Western studies showed relatively high functionality on the ALSFRS and a shorter disease duration compared to those in the present study, patients with ALS in Korea seem to experience more decreased QOL than their Western counterparts. That is, the more deteriorated physical function and longer illness experience might be the reason for

the lower QOL score among ALS patients in this study.

The caregiver's mean McGill QOL score in this study was also relatively low compared to other western population. The mean McGill QOL score for ALS caregivers was 7.3 (Gauthier et al., 2007). Among the 4 domains measured for QOL, physical symptoms rated the lowest in this study, corresponding with the result of increased physical caregiver burden as shown in caregiver burden scores. Gauthier et al.'s longitudinal study (2007) exploring the time trends of QOL among ALS caregivers presented that quality of life decreased as the patient's disease worsened. This study implies that patients' relatively decreased functional status as compared to that reported in the Western study could lead the decreased quality of life scores among ALS caregivers in this study.

Hopelessness was measured for both patients and caregivers. The mean score of hopelessness was 11.87 (SD=4.72), indicating that ALS patients in this study experienced a moderate level of hopelessness. One Western study reported a lower Beck Hopelessness score (mean=5.8) (Chio et al., 2004). The mean score was 6.8 in the study done by Plahuta and her colleagues (2002). Both studies reported that ALS patients experienced mild hopelessness. According to the quantitative relational study by Ganzini et al. (1999), suffering was associated with hopelessness among ALS patients.

Caregivers' mean hopelessness score was 7.21 (SD= 3.93) in this study, meaning that the caregivers experienced a mild level of hopelessness. This descriptive statistic shows that both patients and caregivers experience deteriorate QOL and hopelessness during their illness experience, but they might perceive the future differently. Patients' perception of future might be associated with their pending deaths, but caregivers might experience the coexistence of despair and hope in their perception for the future.

The present study shows that ALS patients and their caregivers experience deteriorated QOL and hopelessness throughout the disease journey. It is evident that such patients and the caregivers need immediate and effective interventions to improve QOL and lessen hopelessness.

Limitation of the study

The methodological limitations of this study include sample selection and sample size. The purposive convenient sampling was the main strategy used for recruitment in this study. The

main mechanism of recruiting was through the KALSA website. Through this community-based recruitment process, the participants in this study are considered the chronic status of ALS patients and their caregivers. The average length of illness was about 57 months (more than 4 years). Despite the efforts to collect participants in diverse stages of ALS, it seems that the study participants are biased to presenting a chronic status of ALS. The results of the descriptive statistics are limited when representing the ALS population due to the small number of participants in the study. The use of convenience sampling and the small size of the sample may limit the generalizability of the findings to persons with similar characteristics.

CONCLUSION

This study depicted general and disease specific characteristics, hopelessness, and QOL of ALS patients in South Korea. The ALS caregivers' hopelessness, QOL, and caregiver burden were also described. Since the cause is not known and curative treatment is yet unavailable, improving QOL and lessen hopelessness should be the main aims to support these patients and their caregivers. In addition, ALS caregivers should be included as a unit of care and support considering QOL interventions. Improving the QOL through comprehensive medical and psychosocial interventions must be the primary goals for ALS patient care since a cure is unavailable. For the enhancement of the QOL in ALS patients, it is important to understand the QOL status of primary caregivers of ALS patients that might affect patients' QOL. The findings add to the body of knowledge on patients with ALS and their caregivers in Korea and provide rationale for designing therapeutic nursing intervention programs to lessen hopelessness and improve QOL with this population in Korea.

References

- Beck, A. T., Weissman, A., Lester, D., & Trexler, L. (1974). The measurement of pessimism: The hopelessness scale. *Journal of Consulting and Clinical Psychology, 42*(6), 861-865.
- Carvalho, M., Schwartz, M. S., & Swash, M. (1995). Involvement of the external anal sphincter in amyotrophic lateral sclerosis. *Muscle Nerve, 18*(8), 848-853.
- Cedarbaum, J. M., & Stambler, N. (1997). Performance of the Amyotrophic Lateral Sclerosis Functional Rating Scale

- (ALSFRS) in multicenter clinical trials. *Journal of the Neurological Sciences*, 152(Suppl 1), S1-9.
- Cedarbaum, J. M., Stambler, N., Malta, E., Fuller, C., Hilt, D., Thurmond, B., & Nakanishi, A. (1999). The ALSFRS-R: A revised ALS functional rating scale that incorporates assessments of respiratory function. *Journal of the Neurological Sciences*, 169(1), 13.
- Charles, T., & Swash, M. (2001). Amyotrophic lateral sclerosis: Current understanding. *Journal of Neuroscience Nursing*, 33(5), 245-253.
- Chi, A., Gauthier, A., Montuschi, A., Calvo, A., Di Vito, N., Ghiglione, P., & Mutani, R. (2004). A cross sectional study on determinants of quality of life in ALS. *Journal of Neurology, Neurosurgery, and Psychiatry*, 75(11), 1597-1601.
- Chio, A., Gauthier, A., Calvo, A., Ghiglione, P., & Mutani, R. (2005). Caregiver burden and patients' perception of being a burden in ALS. *Neurology*, 64(10), 1780.
- Cohen, S. R., Mount, B. M., Strobel, M. G., & Bui, F. (1995). The McGill Quality of Life Questionnaire: A measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliative Medicine*, 9(3), 207-219.
- Ferrell, B., Grant, M., Schmidt, G.M., Rhiner, M., Whitehead, C., Fonbuena, P., et al. (1992). The meaning of quality of life for bone marrow transplant survivors. Part I. The impact of bone marrow transplant on quality of life. *Cancer Nursing*, 15(3), 153-160.
- Ganzini, L., Johnston, W. S., & Hoffman, W. F. (1999). Correlates of suffering in amyotrophic lateral sclerosis. *Neurology*, 52(7), 1434-1440.
- Ganzini, L., Johnston, W. S., McFarland, B. H., Tolle, S. W., & Lee, M. A. (1998). Attitudes of patients with amyotrophic lateral sclerosis and their caregivers toward assisted suicide. *New England Journal of Medicine*, 339(14), 967-973.
- Gauthier, A., Vignola, A., Calvo, A., Cavallo, E., Moglia, C., Sellitti, L., et al. (2007). A longitudinal study on quality of life and depression in ALS patient-caregiver couples. *Neurology*, 68(12), 923-926.
- Goldstein, L. H., Atkins, L., Landau, S., Brown, R., & Leigh, P. N. (2006). Predictors of psychological distress in carers of people with amyotrophic lateral sclerosis: A longitudinal study. *Psychological Medicine*, 36(6), 865-876.
- Gordon, P. H., Miller, R. G., & Moore, D. H. (2004). ALSFRS-R. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders*, 5(Suppl 1), 90-93.
- Kim, H. S., Gu, K. S., Yun, H. Y., Lee, G. C., Choi, S. Y., Lee, S. W., et al. (2007). Validation study of the Korean version of the McGill Quality of Life Questionnaire. *Palliative Medicine*, 21(5), 441-447.
- Kim, S. H. (2006). Diagnosis and Therapeutic Strategies of Amyotrophic Lateral Sclerosis. *Hanyang Medical Reviews*, 26(1), 44-51.
- Mitsumoto, H. (1997). Diagnosis and progression of ALS: Amyotrophic lateral sclerosis standard of care consensus conference. *Neurology*, 48(Suppl. 4), S2-S8.
- Mitsumoto, H., & Rabkin, J. G. (2007). Palliative care for patients with amyotrophic lateral sclerosis: "Prepare for the worst and hope for the best". *JAMA: The Journal of the American Medical Association*, 298(2), 207-216.
- Neudert, C., Wasner, M., & Borasio, G. D. (2004). Individual quality of life is not correlated with health-related quality of life or physical function in patients with amyotrophic lateral sclerosis. *Journal of Palliative Medicine*, 7(4), 551-557.
- Oh, H., Sin, M.-K., Schepp, K. (in press). Depressive symptoms and functional impairment among amyotrophic lateral sclerosis patients in South Korea. *Rehabilitation Nursing Journal*.
- Park, K. H., Kim, H. Y., Nam, Y. H., K, Joo, I. S., Sung, J. J., & Kim, S. H. (2006). Preliminary study on clinical characteristics and caregivers' burden of Korean patients with amyotrophic lateral sclerosis: Survey based on database of Korea ALS association. *Journal of Korean Neurology Association*, 24(3), 252-259.
- Paek, S. (2005). *A study on the burden of family caregivers of amyotrophic lateral sclerosis patients*. Unpublished master's thesis. Yonsei University, Seoul.
- Plahuta, J. M., McCulloch, B. J., Kasarskis, E. J., Ross, M. A., Walter, R. A., & McDonald, E. R. (2002). Amyotrophic lateral sclerosis and hopelessness: psychosocial factors. *Social Science & Medicine*, 55(12), 2131-2140.
- Rabkin, J. G., Wagner, G. J., & Del Bene, M. (2000). Resilience and distress among amyotrophic lateral sclerosis patients and caregivers. *Psychosomatic Medicine*, 62(2), 271.
- Rabow, M. W., Hauser, J. M., & Adams, J. (2004). Supporting family caregivers at the end of life: "They don't know what they don't know". *JAMA: Journal of the American Medical Association*, 291, 483-491.
- Robbins, R. A., Simmons, Z., Bremer, B. A., Walsh, S. M., & Fischer, S. (2001). Quality of life in ALS is maintained as physical function declines. *Neurology*, 56(4), 442-444.
- Shin, M. S., Park, K. B., Oh, K. J., & Kim, Z. S. (1990). A study of suicidal ideation among high school students: The structural relation among depression, hopelessness, and suicidal ideation. *Korean Journal of Clinical Psychology*, 9(1), 1-19.
- Simmons, Z., Bremer, B. A., Robbins, R. A., Walsh, S. M., & Fischer, S. (2000). Quality of life in ALS depends on factors other than strength and physical function. *Neurology*, 55(3), 388-392.
- Simmons, Z., Felgoise, S. H., Bremer, B. A., Walsh, S. M., Hufford, D. J., Bromberg, M. B., et al. (2006). The ALSSQOL: Balancing physical and nonphysical factors in assessing quality of life in ALS. *Neurology*, 67(9), 1659-1664.
- Suh, M. H., & Oh, K. S. (1993). A study of well-being in caregivers caring for chronically ill family members. *Journal of Korean Academy of Nursing*, 23(3), 467-486.