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The amyotrophic lateral sclerosis supportive care needs assessment instrument: Development and psychometric evaluation

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Abstract

Objective. The aim of the study is to develop an amyotrophic lateral sclerosis supportive care needs (ALSSCN) instrument based on Fitch's Supportive Care Needs Framework and to test its psychometric properties.

Method. This study consists of three parts: (1) item generation from the literature review and qualitative interview; (2) content validation; and (3) psychometric evaluation of the instrument. Participants who were diagnosed with ALS ($n = 139$) were recruited from two ALS clinics in Seoul, Korea, and Busan, Korea for the psychometric testing.

Result. The ALSSCN consisted of 37 items with seven domains: physical, psychological, emotional, spiritual, social, informational, and practical needs. The Cronbach's alpha of each domain ranged from 0.61 (social needs) to 0.90 (emotional needs). The intra-class correlation coefficient for test-retest was 0.89, indicating good test-retest reliability. The overall ALSSCN was significantly negatively correlated with the quality of life, which supported convergent validity. Confirmatory factor analysis of the ALSSCN supported a seven-factor model.

Significance of results. The ALSSCN has acceptable internal consistency, stability, and content and construct validity in a Korean ALS population. ALSSCN is a psychometrically sound measure and can be adopted by healthcare professionals, researchers, and administrators to comprehensively assess the perceived supportive care needs of patients with ALS.

Introduction

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease characterized by progressive loss of the upper and lower motor neurons at the spinal or bulbar level (Zarei et al., 2015). Patients with ALS experience symptoms including muscle weakness, atrophy, spasticity, and bulbar symptoms such as dysphagia or dysarthria (Clarke & Levine, 2011). Because of progressive deterioration of these symptoms throughout the disease's course, patients with ALS are severely limited in mobility and eventually have respiratory failure.

ALS has an immense impact on the physical function and psychological well-being of the patients. Because there is no curative treatment, the goal of caring for ALS patients is maximizing the quality of life (QOL) and minimizing the disease burden by providing the best supportive care possible (Galvin et al., 2016; Oh et al., 2015). Each ALS patient requires different aspects of supportive care because of individually different contexts and unique situations as well as the heterogeneity in clinical features among patients (Sabatelli et al., 2013). Therefore, assessing and considering ALS supportive care needs may enable health professionals to provide patient-centered care in which resources and supports are tailored to meet the need on a case-by-case basis (Freeman et al., 2014). Using an instrument to identify such needs may be the first step toward patient-centered care.

In recent decades, many patient-reported outcome measurements (PROMs) were developed to assess needs. PROMs have been increasingly used in clinical settings because the captured information comes directly from the patient (Howell et al., 2015). These needs assessments allow identification of particular areas that patients and their families consider important and where they need help and support (Waller et al., 2010). There are several condition-specific PROMs that assess needs according to specific disease type, severity, and culture in cancer care (Richardson et al., 2007) and also in neurological conditions (Mak et al., 2007; Ponzio et al., 2015). However, so far there is no scale assessing supportive care needs for the ALS population; the most ALS-specific PROMs are those that measure QOL (Jenkinson et al, 1999; Simmons et al., 2006).

A recent scoping review (Oh & Kim, 2017) examined supportive care needs of ALS patients and families; these needs were categorized into Fitch's Supportive Care Needs Framework (SCNF) (Fitch, 2008). Fitch defined supportive care as the provision of services necessary to meet the patient's physical, emotional, social, psychological, informational, spiritual, and

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practical needs (Fitch, 2008). This framework is widely used not only for cancer care, but also for various chronic conditions (MacIsaac et al., 2010; Pelentsov et al., 2015). Therefore, the aim of the study is to develop an amyotrophic lateral sclerosis supportive care needs (ALSSCN) assessment instrument based on SCNF and to test its psychometric properties. This study consists of three parts: (1) item generation; (2) content validation; and (3) psychometric evaluation of the instrument.

Methods

Item generation

The exploration of supportive care needs among patients began with an ALS literature review and then a subsequent qualitative interview. In the literature review step, 37 articles were reviewed that had been included in the previous scoping review (Oh & Kim, 2017) conducted by this study team. To reflect upon the Korean healthcare system and culture, literature regarding supportive care needs of ALS was searched from KoreaMed and Google, and one article and one patient guidebook were added. Preliminary items were devised by two researchers from a total of 38 articles and one patient guidebook.

In the qualitative interview step, participants were recruited from a territory hospital ALS clinic (Hanyang University Hospital, Seoul, Korea). Patients who were included were diagnosed with definite, probable, probable laboratory-supported, or possible ALS, according to the El Escorial revised criteria (Brooks et al., 2000); were Korean; and were older than age 20 years. Family members who lived with and had kinship with the patient were included. A maximum variation sampling strategy was used to ensure diversity of gender, ALS type, and disease stage. Six ALS patients (four males and two females; mean age, 52.3 years) and 11 family members (six males and five females; mean age, 52.1 years) were enrolled in the interviews. The interviews were conducted in a private room in the hospital by one researcher from June to August 2016. Participants were asked about their experiences of living with ALS and their difficulties and needs. Interviews were conducted until the data reached a saturation point. Interviews were digitally audio-recorded and transcribed with permission of the participants. Findings were analyzed and preliminary items were devised.

A pool of items from the literature review and qualitative interviews were revised and duplicated items were removed; a total of 45 items remained as a preliminary version. Then the items were categorized according to the SCNF domains. The response categories were rated on a 4-point Likert scale: 1 = no assistance, 2 = little assistance, 3 = moderate assistance, and 4 = considerable assistance.

Content validation

This preliminary version of a questionnaire was reviewed by a panel of 12 experts (four professors in neurology, three professors of nursing, two nurse specialists in home care, one professor of hospice, one coordinator nurse in an ALS clinic, and one clinical psychologist). The panel evaluated the content validity, assigning each item a rating ranging from 1 (not relevant) to 4 (very relevant). The content validity index is the percentage of those items indicated as a 3 or 4 by the experts (Lynn, 1986). Ten items were below the cutoff of 80% and eight items were removed. Two items were revised and included in the initial questionnaire during the researchers' discussion because these items frequently appeared in both the literature and interviews.

To enhance the readability of the questionnaire, we asked two elementary school teachers who teach sixth-grade students to provide a review so that that materials would be understandable at a sixth-grade reading level (DeVellis, 2016). They reviewed and suggested changes for some words. We also identified the difficulty of each word through an online dictionary (http://www.natmal.com). If a word was at a level 4 or above, we changed the word to an easier one. Finally, face validity was approved after a pilot test was performed with three patients and two family members at an ALS outpatient visit. It took these participants approximately 10–20 minutes to complete and no item was changed following this step.

For publication purposes, we translated the questionnaire from Korean to English via forward and backward translation. First, a Korean immigrant nurse and a professional translator independently translated Korean to English and the researchers made a common version. Second, another professional translator translated the English to Korean. The researchers checked the differences between the original and back-translated versions and agreed on a final English version (Appendix 1).

Psychometric evaluation

Data collection

Participants with ALS were recruited from two ALS clinics (Hanyang University Hospital, Seoul, and Busan Paik Hospital, Busan, Korea), between November 2016 and May 2017. Using a ratio of five cases per item (Devellis, 2016), the number of participants was 5×37, or 185 participants. Participants were eligible for this study if they were diagnosed with definite, probable, probable laboratory-supported, or possible ALS according to the El Escorial revised criteria (Brooks et al., 2000); if they were Korean; and if they were older than age 20 years. Participants were excluded if they had been diagnosed with frontotemporal dementia, severe depression, or schizophrenia. Researchers met with the participants and explained the purpose and procedures of the study. If a participant gave consent, the patient was asked to fill out self-reported questionnaires. If a patient could not check off items on the questionnaire because of muscle weakness, the researchers or family members recorded the patient's response. Patients who visited the clinic approximately 4 weeks after the first administration were included to assess the test-retest reliability of the ALSSCN. Also, patient demographics (age, sex, education level, religious belief) and clinical features (site of symptoms onset, disease duration, ALS type, ALS stage) (Roche et al., 2012), and ALS Functional Rating Scale-Revised (ALSFRS-R) (Cedarbaum et al., 1999) were collected from medical chart review.

Validating instruments

Amyotrophic Lateral Sclerosis-Specific Quality of Life - revised instrument (ALSSQOL-R). ALSSQOL-R was used to determine convergent validity, was developed by Simmons et al. (2006), and validated in a Korean version by Oh et al. (2017). It is used as an instrument to measure global QOL in an ALS population. The ALSSQOL-R consists of 46 items with six subscales (Negative emotion, interaction with people and environment, intimacy, religiosity, physical symptoms, and bulbar function). Each item is assessed on an 11-point numeric scale (0–10), and several items require transposing, specifically items 1–10, 17, 22,

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24, 25, 28, 31, and 34. The total score is then divided by 46. An average total score varies from 0 (worst) to 10 (best).

McGill Quality of Life Single-Item Scale (MQOL-SIS). MQOL-SIS was used to determine convergent validity. MQOL-SIS was developed by Cohen et al. (1995) and is widely used to measure global QOL in palliative care. The MQOL-SIS consists of a single question that asks patients their overall assessment of their own global QOL (including physical, emotional, social, spiritual, and financial aspects) on a scale from 0 (very bad) to 10 (excellent). The MQOL-SIS is highly correlated with the overall score of the MQOL and has been widely used in patients with life-threatening illnesses including ALS.

King's clinical stage for ALS. King's clinical stage was used to determine discriminant validity. King's clinical stage was developed by Roche et al. (2012). It classifies disease burden into five stages, with stage 1 being symptom onset and stage 5 being death, according to clinical involvement and significant nutritional or respiratory failure.

- Stage 1: Involvement of first clinical region
- Stage 2: Involvement of a second clinical region
- Stage 3: Involvement of a third clinical region
- Stage 4: Need for gastrostomy or non-invasive ventilation
- Stage 5: Death

Data analysis

Statistical tests were carried out using IBM SPSS Statistics 21.0 (IBM, Armonk, NY); the structural equation modelling program IBM SPSS Amos 22.0 (IBM) was used to perform the confirmatory factor analysis. For all statistical tests, a two-sided alpha of 0.05 was considered. The missing value was replaced with its average value. Cronbach's alpha coefficient was implemented to evaluate the internal consistency of the total scale and each domain of the ALSSCN; a Cronbach's alpha coefficient of 0.70 or better was considered acceptable (Nunnally, 1978). Intra-class correlation coefficients (ICC) were calculated to determine the test-retest reliability. Convergent validity was examined using Pearson's correlation coefficients between overall ALSSCN and ALSSQOL-R and MQOL-SIS. Known-group validity was assessed by difference using analysis of variance of ALSSCN, according to King's clinical stage. The item-to-domain and domain-to-domain correlations were evaluated by calculating Pearson's correlation coefficients. Correlation coefficients less than 0.30, 0.30–0.50, 0.50–0.70, and greater than 0.70 were considered negligible, low, moderate, and high, respectively (Mukaka, 2012). Confirmatory factor analysis was used to examine whether a priori assignment of items to each domain was supported by the data.

Ethics

The Ethics Committee of the Hanyang University Hospital (HYUH 2016-04-045) and Inje University Busan Paik Hospital (IJUBPH 16-0275) granted ethical approval for this study. Informed consent was obtained before participation in the qualitative interview or psychometric test.

Results

Participants

A total of 185 patients with ALS from two ALS clinics were approached. Of these, 139 patients (75.1%) consented to participate. Participant characteristics are shown in Table 1. Participant ages ranged from 29 to 78 years of age, with a mean age of 56.2 years; 44.6% were female. The mean duration of illness was 39.0 months and ALSFRS-R was 32.3. The number of cases for each King's stage was 38 in stage 2, 85 in stage 3, and 16 in stage 4.

Table 1. Participant characteristics

Characteristics	Category	*n* (%) or mean ± *SD*
Age (years)		56.2 ± 10.6
Sex	Female	62 (44.6)
	Male	77 (55.4)
Education (years)		12.0 ± 3.8
Religious beliefs	Christian	27 (19.4)
	Catholic	12 (8.6)
	Buddhist	21 (15.1)
	None	79 (56.8)
Site of symptoms onset	Bulbar	27 (19.4)
	Spinal	112 (80.6)
King's clinical stage	Stage 2	38 (27.3)
	Stage 3	85 (61.2)
	Stage 4	16 (11.5)
Disease duration (months)		39.0 ± 32.9
ALSFRS-R		32.3 ± 9.7

ALSFRS-R, Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised.

ALSSCN

The ALSSCN consisted of 37 items with seven domains representing needs: physical (items 1–11), psychological (items 12–15), emotional (items 16–18), spiritual (items 19–21), social (items 22–24), informational (items 25–29), and practical needs (items 30–37) (Appendix 1). Among 139 participants, 97% responded to all items in the ALSSCN. Ten skipped one item and five skipped two items. Missing data appeared to be missing at random. The mean ALSSCN score was 2.44 ± 0.66. The highest scored domain was informational needs (2.91 ± 0.89), followed by practical needs (2.75 ± 0.93), psychological needs (2.48 ± 0.82), emotional needs (2.41 ± 1.00), social needs (2.18 ± 0.79), physical needs (2.16 ± 0.80), and spiritual needs (2.05 ± 0.89) (Table 2).

Reliability

Cronbach's alpha coefficient of each domain ranged from 0.61 (social needs) to 0.90 (emotional needs) (Table 2). No single item improved the Cronbach's alpha coefficient of each domain. The ICC for test-retest was 0.89 ($p < 0.001$), indicating good test-retest reliability. There was no significant difference in demographic factors between the total group and test-retest group.

Validity

The overall ALSSCN was significantly negatively correlated with the MQOL-SIS ($r = -0.51$, $p < 0.001$) and ALSSQOL-R (r =

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Table 2. Descriptive statistics and Cronbach's alpha of ALSSCN

	Mean	*SD*	Cronbach's α
Overall ALSSCN	2.44	0.66	NA
Physical	2.16	0.80	0.89
Psychological	2.48	0.82	0.76
Emotional	2.41	1.00	0.90
Spiritual	2.05	0.89	0.76
Social	2.18	0.79	0.61
Informational	2.91	0.89	0.87
Practical	2.75	0.93	0.89

ALSSCN, Amyotrophic Lateral Sclerosis Supportive Care Needs; NA, not available.

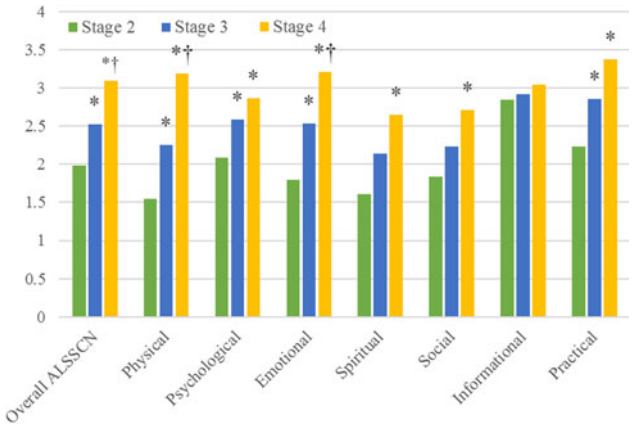


Fig. 1. Differences of ALSSCN according to ALS stage. ALSSCN=Amyotrophic Lateral Sclerosis Supportive Care Needs; Post hoc analysis (Scheffe's test) difference from Stage 2 * and Stage 3 †.

−0.65, $p < 0.001$) (Table 3). These results support the convergent validity of ALSSCN. The significant difference of overall ALSSCN was according to King's stage, indicating acceptable known-group validity. Also, each domain's score was significantly different between King's stages except for the Informational needs domain (Fig. 1).

Domain-to-domain correlations ranged from 0.20 to 0.73. Pearson's correlation coefficients were negligible to moderate except for one pair: psychological and emotional. Item-to-domain correlations represented moderate to high correlations with their assigned domains ranging from 0.61 to 0.94. Confirmatory factor analysis of the ALSSCN supported a seven-factor model: physical, psychological, emotional, spiritual, social, informational, and practical needs. The χ^2 value was 529.28, with 246 degrees of freedom = 2.40, where the comparative fit index = 0.74, the root mean square error of approximation = 0.10, and the closeness-of-fit statistic <0.001. These results are acceptable, considering that the sample size used in this analysis was relatively small.

Discussion

We developed an instrument assessing the supportive care needs of patients with ALS that was based on SCNF and examined its psychometric properties. To the best of our knowledge, ALSSCN is the first disease-specific scale assessing supportive care needs for patients with ALS. The results demonstrated that ALSSCN has acceptable internal consistency, stability, and content and construct validity in a Korean ALS population. Strengths of the study include guidance by a conceptual model and findings from a preliminary study.

ALSSCN consists of 37 items, which has been reduced from the 45 items that were initially generated. This was completed using the standard method of using an expert panel composed of professionals when developing a new scale. The remaining 37 items were considered to be relevant items by the expert panel or authors. The short response time and sixth-grade readability level of this scale support its use as a self-report measure in a multidisciplinary care system. Additionally, the high response rates and minimal missing data indicate good face validity.

In the reliability test, the Cronbach's alpha of the six domains was acceptable, excluding the social domain (0.61). The social domain consisted of three items regarding the social needs of family, relatives, and other patients and all the items were considered relevant to the content. Also, removing an item from this domain to obtain a higher alpha was not possible, because each factor should have at least three items in a scale to be considered as a component (Malfait et al., 2016). Furthermore, the test-retest stability of the ALSSCN was evidenced by ICC (0.89) analysis.

Table 3. Correlations of each ALSSCN domain and convergent validity

	ALSFRS-R	Physical	Psychological	Emotional	Spiritual	Social	Informational	Practical	ALSSQOL-R	MQOL-SIS
Overall ALSSCN	−0.67**	0.79**	0.76**	0.76**	0.68**	0.73 **	0.64**	0.85**	−0.65**	−0.51**
Physical			0.54**	0.56**	0.50**	0.48 **	0.20*.	0.52**	−0.59**	−0.40**
Psychological				0.7 **	0.53**	0.49 **	0.40**	0.55**	−0.56**	−0.45**
Emotional					0.50**	0.55 **	0.39**	0.54**	−0.63**	−0.43**
Spiritual						0.59 **	0.33**	0.47**	−0.26**	−0.36**
Social							0.53**	0.55**	−0.50**	−0.42**
Informational								0.65**	−0.27**	−0.28**
Practical									−0.53**	−0.40**

ALSFRS-R, Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised; ALSSCN, Amyotrophic Lateral Sclerosis Supportive Care Needs; ALSSQOL-R, Amyotrophic Lateral Sclerosis-Specific Quality Of Life-Revised Instrument; MQOL-SIS, McGill Quality of Life Single-Item Scale.
*$p < 0.05$; **$p < 0.01$.

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Although we could not collect test-retest data from the entire sample, there was no significant difference in demographic factors between the test-retest group and the total group.

We could not compare our instrument with a gold standard scale of care needs for ALS to assess concurrent validity. Therefore, we selected validated measures of QOL; we hypothesized that higher supportive care needs are negatively correlated with global QOL (Hwang et al., 2004). This result supported the hypothesis and provided convergent validity of the ALSSCN. Also, this result suggested that the instrument may be helpful in meeting patient care needs that enhance their QOL. Meanwhile, there were differences in the ALSSCN according to disease stage, which supports known-group validity. Because ALS is a rapidly progressive disease, healthcare professionals should provide supportive care in a timely manner, considering individual needs and disease severity because needs can change according to the disease severity. However, there was no difference between stages in informational needs. Also, informational needs had the highest score for the patients in stages 2 and 3. These results indicate that even patients in early stages require more information.

In this study, development of the ALSSCN was guided by SCNF. Although the framework was developed for patients and caregivers of cancer, we used the framework of a previous study (Oh & Kim, 2017); therefore, we conducted confirmatory factor analysis instead of exploratory factor analysis. Despite the small sample size, the results supported this seven-factor model. Also, the higher correlation of each item to its assigned domain supported the construct validity of ALSSCN. Domain-to-domain correlations indicate the independence of each domain; however, there was a high correlation between the psychological needs and emotional needs domains. High correlations between domains might be problematic when using a multivariate approach to analyze associations between domains and outcome variables (Huijg et al., 2014). For this reason, a further study is needed that includes exploratory factor analysis in a large sample.

A weakness of the study is that, as a rule of thumb, five participants per item are needed in developing a new scale (DeVellis, 2016); hence, there should have been at least 185 participants for the 37-item ALSSCN. However, only 139 participants were included by convenience sampling in this study. Because ALS is a rare disease with an incidence of about 2 per 100,000 population (Chio et al., 2013), we could not include a sufficient number of patients. External validity could have been limited by the small sample size and non-random sampling method of this study. Also, for publication purposes, the ALSSCN was translated from Korean to English by forward and backward translation; however, the instrument was developed and psychometrically tested on Korean patients. Literature published mostly in Western countries was reviewed in the item generation step, which should partially compensate for the limitation. Nevertheless, future research is needed to include cross-cultural adaptation. Last, because we did not provide cutoff scores of ALSSCN in this study, further research should provide them to help its interpretation.

Despite these limitations, this study is significant because it lays the foundation for further studies in this area. A supportive care needs assessment for patients with ALS is a fundamental tool to identify population-level needs for care and to provide a robust scientific basis to lobby for resources and policy response. The ALSSCN holds promise for helping clinicians quickly assess which supportive care needs are priorities. Each item of the ALSSCN can be used to find out what is actually needed and can provide a basis for providing practical services to ALS patients; for example, clinicians will refer to rehabilitation or introduce mobility aids to a patient whose mobility score in the ALSSCN has dropped. We suggest using the ALSSCN when patients visit for regular check-ups or at least when the patient's disease stage changes. In conclusion, ALSSCN is a psychometrically sound measure that can be adopted by healthcare professionals, researchers, and administrators to comprehensively assess the perceived supportive care needs of patients with ALS.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1478951517001250.

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Conflict of interest. None.

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