

# Information Needs and Preferences of Family Caregivers of Patients With Amyotrophic Lateral Sclerosis



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## ABSTRACT

**OBJECTIVE:** The aim of this study was to explore the information needs and preferred sources of information of Korean family caregivers of patients with amyotrophic lateral sclerosis (ALS). **METHODS:** Family caregivers of patients with ALS ( $n = 108$ ) completed a structured questionnaire to assess their information needs and preferred sources of information. **RESULTS:** Most of the caregivers obtained health information from Internet searches (89.8%) and healthcare professionals (85.2%). The source rated most helpful was healthcare professionals, and that rated least helpful was broadcast media. Family caregivers who were younger than 50 years and well educated and caregivers of bulbar-onset ALS patients had higher scores of information needs. **CONCLUSION:** Providing information through healthcare professionals and self-support groups could enhance family caregiver satisfaction. Family caregivers who are older and less educated need to be more empowered to be involved in information-based caring, and caregivers of patients with bulbar-onset ALS have substantial information needs.

**Keywords:** amyotrophic lateral sclerosis, care partner, family caregivers, information needs, information preference, nursing

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease characterized by degenerative changes in both upper and lower motor neurons, leading to progressive muscle weakness throughout the course of the disease.<sup>1,2</sup> The most common cause of death is respiratory failure, which occurs, on average, 2 to 4 years after symptom onset<sup>3</sup>; up to 10% of ALS patients survive for more than 10 years.<sup>4</sup> Approximately 30% to 50% of ALS patients experience cognitive impairment.<sup>5</sup> Patients with ALS gradually lose muscle functions, and the disease leads to an increasing need for care.<sup>6</sup> Because care for people with ALS largely takes place in the community, the caregiver role is most commonly assumed by a family member, usually a spouse or partner, who has no previous experience in this role.<sup>7</sup> Family caregivers are

key figures in care provision, providing emotional and physical support to patients and playing a role in clinical decision making in ALS treatment.<sup>8</sup>

Information about the course of the disease for the caregivers and the development of skills to adequately care for the patient are necessary to improve their quality of care and decrease the caregivers' burden.<sup>9</sup> However, a lack of information can evoke negative emotional reactions, such as anxiety, depression, and uncertainty, in caregivers.<sup>10,11</sup> Family caregivers frequently search for information about ALS, beginning with the prediagnosis phase through decision making regarding advanced directives and end-of-life care.<sup>11</sup> They need information about various topics such as the disease itself and its process, and regarding the healthcare system, including availability of respite care, counseling, and access to trained professional caregivers.<sup>10,12</sup> Previous studies have revealed that caregivers of ALS patients need more information about the condition.<sup>12,13</sup>

ALS is a rare disease with an incidence of 1.59 per 100 000 person-years<sup>14</sup>; there is scarce information that caregivers can access compared with other chronic diseases. Moreover, family caregivers of ALS patients need to learn new information as the disease's relentless deterioration progresses. In the later stages, they need to acquire management skills for home ventilators and enteral feeding. They rely on various information sources besides healthcare professionals, including ordinary people, the Internet, mass media, medical journals, and community resources. A number

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of studies have shown that the need for information is a top priority among caregivers of various chronic diseases.<sup>15</sup> Meeting family caregivers' information needs is an important aspect in caring for chronic diseases and is a stepping stone for family-centered care.<sup>16</sup> Therefore, specific information needs and preferred sources of information need to be identified.

Whereas extensive research has been conducted on the psychosocial aspects of family caregivers of ALS patients, only a few investigations regarding information needs and information-seeking behaviors have been conducted in an ALS population, primarily in Europe.<sup>12,13</sup> However, there are large differences across Asian countries in terms of healthcare systems, social services, and family culture. Therefore, the aim of this study was to explore the information needs and preferred sources of information of Korean family caregivers of patients with ALS.

## Methods

This study used a descriptive survey design to identify the information needs and preferred sources of information for family caregivers of people with ALS. A convenience sample of 108 family caregivers was recruited for this cross-sectional study during routine visits to the ALS Clinic of Hanyang University Hospital, Seoul, Korea. A family caregiver was defined as an adult family member who cohabitated with the patient with ALS and who self-identified as the primary caregiver. Data collection was initiated in March 2018 and completed in December 2019. This study was approved by the institutional review board of Hanyang University Hospital. After obtaining consent, the family caregivers completed a self-administered paper-based questionnaire.

Family caregivers' demographic data were collected, which included age, sex, marital status, educational attainment, and relationship to the patient. Patients' demographic and clinical data were collected, which included age, sex, disease duration, onset region, gastrostomy, respiratory support, and the Korean version of the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R) scores.<sup>17</sup> The ALSFRS-R is the most widely used surrogate marker of disease progression of ALS in clinical research and allows for assessment of the functional status of bulbar, upper and lower limb motor, and respiratory function. The revised scale contains 12 items rated on a 5-point Likert scale (0–4) for a possible total score range of 0 to 48; the higher the score, the better the patient's functional status.<sup>17</sup>

To measure the information needs of family caregivers of patients with ALS, the questionnaire was developed by the researchers based on previous studies<sup>8,11–13</sup> and educational materials for ALS patients and their

## 90% of caregivers obtained information about ALS from the Internet.

family caregivers from the ALS Association website.<sup>18</sup> This scale consists of 3 subdomains (diagnosis and treatment, symptom management and self-care, and social support resources). This 17-item questionnaire is evaluated on a 4-point Likert scale from 0 (I do not want to know at all) to 4 (I want to know very much). Before administering the questionnaire, the content validity index of this scale was evaluated by an expert panel consisting of a professor of nursing, an expert with a doctorate in nursing, 2 neurologists, and 2 motor neuron disease nurse specialists. In the content validity testing by the expert panel, all items of the scale were evaluated as “very relevant” or “relevant” (content validity index, 1.00). To establish information source preferences, family caregivers were asked the following questions: “When you were looking for information related to ALS patient care, where did you find it?” and “How helpful was each information source? (from the least helpful = 0 to most helpful = 4).” Response options for the first question included healthcare professionals, broadcast media (TV/radio/newspapers), relatives and friends, self-support groups, Internet searches, online patient communities, and offline lectures. We provided additional open fields for other aspects of information needs at the end of the questionnaire, but none of the participants added any free responses to these fields.

The data were analyzed using the IBM SPSS v.23.0 for Windows. Information needs, information resource preferences, and sociodemographic and clinical characteristics were reported as frequencies and percentages for categorical data and as means and standard deviation for continuous variables. The independent *t* test was used to examine the differences between participants' characteristics and information needs, and effect size was calculated using Cohen's *d*.<sup>19</sup> All tests were 2-tailed. Statistical significance was set to  $P < .05$ .

## Results

Characteristics of family caregivers and their patients are shown in Supplemental Digital Content 1, available at <http://links.lww.com/JNN/A269>. Caregiver ages ranged from 21 to 73 years, with a mean (SD) age of 47.32 (11.31) years; 69.4% were female. The caregiver was a spouse (52.8%), an adult child (38.9%), or another relative (parent, sister, brother) (8.3%) of the patient. The patients had a mean (SD) age of 58.19 (10.28) years, 46.3% were female, and 70.4% had spinal-onset ALS.

The mean (SD) of the disease duration was 37.36 (30.85) months, and the mean (SD) of the ALSFRS-R score was 28.06 (12.26).

Most caregivers obtained health information from Internet searches (89.8%) and healthcare professionals (85.2%). Family caregivers also sought information from the broadcast media (46.3%), online patient communities (42.6%), relatives and friends (36.1%), self-support groups (25.0%), and offline lectures (25.0%). The source rated most helpful was healthcare professionals ( $3.94 \pm 1.17$ ) followed by online patient communities ( $3.59 \pm 1.36$ ) and self-support groups ( $3.56 \pm 0.87$ ), and the least helpful source was the broadcast media ( $2.60 \pm 1.11$ ).

The total information needs score of family caregivers was  $3.33 \pm 0.53$  out of 4, with the highest score in symptom management and self-care ( $3.47 \pm 0.56$ ) followed by diagnosis and treatment ( $3.25 \pm 0.67$ ) and social support resources ( $3.19 \pm 0.68$ ). The items with the highest information needs were clinical trials ( $3.63 \pm 0.72$ ) and care in emergency situations ( $3.63 \pm 0.58$ ) followed by symptom management ( $3.61 \pm 0.71$ ), a social welfare system for ALS ( $3.55 \pm 0.72$ ), emotional care ( $3.54 \pm 0.73$ ), and complementary and alternative medicine ( $3.47 \pm 0.69$ ; Table 1).

The associations between the characteristics of family caregivers and patients and information needs are presented in Table 2. The total information needs ( $t = 2.02$ ,  $P = .046$ ) and symptom management and self-care ( $t = 1.99$ ,  $P = .049$ ) were high for family caregivers younger than 50 years, and symptom management and self-care ( $t = 2.06$ ,  $P = .042$ ) and social support resources ( $t = 2.05$ ,  $P = .043$ ) were higher for family caregivers with an education level of college or higher, with effect sizes of 0.38 to 0.40. Family caregivers of bulbar-onset ALS patients had higher scores in total information needs ( $t = 3.10$ ,  $P = .003$ ) and all subdomains: diagnosis and treatment ( $t = 2.63$ ,  $P = .010$ ), symptom management and self-care ( $t = 2.42$ ,  $P = .018$ ), and social support resources ( $t = 2.29$ ,  $P = .024$ ), with effect sizes of 0.45 to 0.61. Other characteristics, including disease duration and severity, were not significantly associated with the information needs of family caregivers.

## Discussion

A limited number of studies have been conducted regarding information-seeking behaviors and the needs of family caregivers of patients with ALS, especially in Asian countries. In Korea, the general public has a high level of education, which has advanced medical care; thus, the results of this study may be applicable to western developed countries with characteristics similar to these. The results of this study suggest that,

despite obtaining information from various sources, family caregivers need further information about ALS. Interestingly, the high level of information needs was found regardless of disease severity.

The great majority of family caregivers searched the Internet to obtain information, and this pattern was also observed in previous studies conducted in European countries.<sup>12,13</sup> However, the Internet is perceived as a less-than-helpful source by the caregivers. This can be explained by a lack of reliable websites for patients with ALS, especially for non-English speakers; thus, many caregivers may struggle to identify valid and helpful sources from among the great volume of information available in web portals. Another important issue is the variation of the information available online.<sup>10</sup> Caregivers sometimes become confused because of the inconsistency of the information retrieved from the Internet. In this study, the results suggested that healthcare professionals provided the most helpful information, followed by online patient communities and self-support groups. The reason for this is likely that ALS is a rare disease, and participants found that information from experts or people with the same experience was valuable. Furthermore, interestingly, support groups were one of the least accessed information sources but were rated as one of the most helpful. A previous study also found that mutual support helped participants lessen emotional distress as well as exchange information and advice on care management.<sup>20</sup> Therefore, healthcare professionals should meet family caregivers' information needs with multidisciplinary collaboration,<sup>21</sup> and they should refer and introduce the family to self-support groups.

Total information needs ranked 3.33 out of 4 in our analysis, indicating relatively high needs. The highest scored item was clinical trials, probably because ALS has no cure and patients and caregivers of ALS are looking for new treatments. Similarly, a previous study reported that both patients and caregivers indicated that the most important information to be given was current research on ALS.<sup>12</sup> In addition, care in emergency situations, symptom management, and social welfare systems for ALS patients were what family caregivers considered to be important aspects of what they needed. Such practical information needs have also been found to be desired by a large number of patients and families in studies of the online patient community.<sup>10</sup>

Factors associated with the level of information needs were identified as the age and the educational attainment of the family caregivers. Older and less educated family caregivers had fewer information needs, which possibly resulted in less use of knowledge about patient care and diminished patient outcomes.<sup>22</sup> Therefore, healthcare professionals need to encourage and empower older and less educated family caregivers to become more

**TABLE 1.** Family Caregivers' ALS-Related Informational Needs (N = 108)

Information Domains	Type of Information	Mean $\pm$ SD	Rank
Domain 1 Diagnosis and treatment	1. Specialized hospital for ALS	3.15 $\pm$ 1.05	15
	2. Diagnostic procedures	2.64 $\pm$ 1.28	17
	3. Causes of ALS	3.38 $\pm$ 0.98	10
	4. Therapeutic effects and side effects of medications	3.27 $\pm$ 0.86	12
	5. Prognosis	3.45 $\pm$ 0.77	7
	6. Clinical trials	3.63 $\pm$ 0.72	1
	Domain 1 subtotal	3.25 $\pm$ 0.67	
Domain 2 Symptom management and self-care	7. Symptom management	3.61 $\pm$ 0.71	3
	8. Emotional care	3.54 $\pm$ 0.73	5
	9. Diet	3.40 $\pm$ 0.90	9
	10. Physical activity or exercise	3.45 $\pm$ 0.70	7
	11. Complementary and alternative medicine	3.47 $\pm$ 0.69	6
	12. Care in emergency situations	3.63 $\pm$ 0.58	2
	13. Medical supplies or medical equipment	3.18 $\pm$ 0.86	14
	Domain 2 subtotal	3.47 $\pm$ 0.56	
Domain 3 Social support resources	14. Rehabilitation or long-term care facilities	3.31 $\pm$ 0.95	11
	15. Social welfare system for ALS	3.55 $\pm$ 0.72	4
	16. Self-support group participation	2.68 $\pm$ 0.95	16
	17. Reliable information resources	3.22 $\pm$ 0.87	13
	Domain 3 subtotal	3.19 $\pm$ 0.68	
Total		3.33 $\pm$ 0.53	

Abbreviation: ALS, amyotrophic lateral sclerosis.

involved in information-based care. Because older and less educated people may face challenges understanding medical terminology, tailored information should be provided. Interestingly, family caregivers of patients with bulbar-onset ALS had higher levels of information needs in all subdomains, with medium effect sizes. Some possible explanations of this finding might include the following: bulbar-onset ALS is rarer than spinal-onset ALS, with the latter being the predominant type accounting for 70% of the cases among patients, whereas bulbar-onset ALS accounts for only 25%;<sup>23</sup> bulbar-onset ALS manifests with a more aggressive and rapid clinical course;<sup>24</sup> and bulbar symptoms, especially communication problems, greatly increase the burden of the disease. However, further study will be needed to understand the reasons for the higher information needs of family caregivers caring for bulbar-onset ALS patients, as indicated in these results.

Besides these 3 factors, other demographics and clinical features had no significant association with the level of information needs. In other diseases, information needs are known to be high at the early stage of the disease and to decline over time,<sup>25,26</sup> but the results of this study indicate a different trend that

may be due to the disease characteristics of ALS. Caregivers need to acquire ongoing care skills as the patient's condition deteriorates, because they need to know how to help the patient in their daily life in terms of how to perform enteral feeding and how to manage home ventilators. This pattern was also found in a study of patients with ALS whose informational needs did not differ according to disease severity, whereas other subdomains of supportive care needs significantly increased in the advanced stage.<sup>27</sup> Therefore, healthcare professionals should note that family caregivers of ALS have a high level of information needs regardless of disease severity or disease duration and, importantly, that a family-centered approach is appropriate for effective care.

This study has several limitations. Data were collected from 1 multidisciplinary clinic, so this study's results have potentially limited generalizability. Caregivers who have no affiliation with a multidisciplinary clinic could have different information needs (eg, early-stage patients may visit a clinic without caregivers). However, demographics (of both patients and caregivers) in this study were similar to those of a previous Korean caregiver study that collected data from home visits,<sup>28</sup> and this may partially compensate for



**TABLE 2.** Difference of Informational Needs in Family Caregivers of ALS Patients (N = 108)

Variables		Total Informational Needs		Diagnosis and Treatment		Symptom Management and Self-care		Social Support Resources	
		Mean ± SD	t (P)	Mean ± SD	t (P)	Mean ± SD	t (P)	Mean ± SD	t (P)
<b>Caregivers' characteristics</b>									
Age, y	<50	3.41 ± 0.53	<b>2.02 (.046)</b>	3.33 ± 0.70	1.45 (.150)	3.56 ± 0.51	<b>1.99 (.049)</b>	3.28 ± 0.75	1.66 (.100)
	≥50	3.21 ± 0.51		3.14 ± 0.62		3.34 ± 0.60		3.07 ± 0.55	
Sex	Male	3.27 ± 0.41	−0.69 (.493)	3.20 ± 0.57	−0.52 (.605)	3.42 ± 0.40	−0.60 (.549)	3.11 ± 0.64	−0.77 (.443)
	Female	3.35 ± 0.58		3.27 ± 0.71		3.48 ± 0.61		3.22 ± 0.69	
Marital status	Single	3.26 ± 0.55	−0.73 (.469)	3.23 ± 0.73	−0.21 (.831)	3.34 ± 0.59	−1.38 (.170)	3.18 ± 0.67	−0.12 (.906)
	Partnered	3.35 ± 0.52		3.26 ± 0.64		3.51 ± 0.54		3.19 ± 0.68	
Educational Attainment	High school or less	3.20 ± 0.56	−1.90 (.061)	3.18 ± 0.63	−0.88 (.384)	3.33 ± 0.64	<b>−2.06 (.042)</b>	3.02 ± 0.70	<b>−2.05 (.043)</b>
	College or above	3.40 ± 0.50		3.30 ± 0.69		3.55 ± 0.48		3.29 ± 0.65	
Relationship with patient	Spousal	3.28 ± 0.52	−0.92 (.359)	3.19 ± 0.61	−1.05 (.295)	3.42 ± 0.58	−0.98 (.331)	3.18 ± 0.58	−0.10 (.921)
	Nonspousal	3.37 ± 0.54		3.32 ± 0.73		3.52 ± 0.53		3.20 ± 0.77	
<b>Patients' characteristics</b>									
Age, y	<50	3.48 ± 0.41	1.49 (.138)	3.38 ± 0.51	0.98 (.327)	3.62 ± 0.38	1.14 (.160)	3.38 ± 0.58	1.46 (.148)
	≥50	3.29 ± 0.55		3.22 ± 0.70		3.43 ± 0.59		3.14 ± 0.69	
Sex	Male	3.30 ± 0.54	−0.44 (.663)	3.29 ± 0.61	0.56 (.574)	3.42 ± 0.60	−0.99 (.324)	3.14 ± 0.67	−0.87 (.387)
	Female	3.35 ± 0.52		3.21 ± 0.73		3.52 ± 0.50		3.25 ± 0.68	
Disease duration, mo	<24	3.33 ± 0.60	0.12 (.908)	3.24 ± 0.78	0.15 (.879)	3.52 ± 0.57	0.71 (.479)	3.15 ± 0.83	0.41 (.684)
	≥24	3.32 ± 0.49		3.26 ± 0.60		3.44 ± 0.55		3.21 ± 0.58	
Onset region	Bulbar	3.53 ± 0.37	<b>3.10 (.003)</b>	3.51 ± 0.50	<b>2.63 (.010)</b>	3.63 ± 0.38	<b>2.42 (.018)</b>	3.38 ± 0.40	<b>2.29 (.024)</b>
	Spinal	3.24 ± 0.56		3.14 ± 0.70		3.40 ± 0.61		3.11 ± 0.74	
Gastrostomy	Yes	3.37 ± 0.47	0.47 (.637)	3.35 ± 0.63	0.86 (.390)	3.39 ± 0.52	0.73 (.464)	3.35 ± 0.42	1.80 (.077)
	No	3.31 ± 0.55		3.22 ± 0.68		3.49 ± 0.57		3.14 ± 0.73	
Respiratory support	No	3.34 ± 0.50	0.76 (.448)	3.26 ± 0.66	0.30 (.765)	3.51 ± 0.51	1.77 (.080)	3.18 ± 0.70	−0.43 (.668)
	NIV or IV	3.24 ± 0.64		3.21 ± 0.74		3.26 ± 0.72		3.25 ± 0.55	

Abbreviations: ALS, amyotrophic lateral sclerosis; IV, invasive ventilation; NIV, noninvasive ventilation.  
 Statistically significant values are in bold.

this limitation. Nevertheless, future research using a multicenter collaboration approach with larger sampling could help confirm these results. Further studies are also needed to examine the associations between patients' outcomes and family caregivers' information needs, and information-seeking behaviors. In addition, the preferences regarding these information sources as well as the accuracy of each source should be evaluated in future studies.

## Conclusion

The findings of this study suggest that providing information through healthcare professionals and self-support groups could enhance the satisfaction of family caregivers. Therefore, using a multidisciplinary approach, it is necessary to develop educational programs that can provide education to patients and their families and to connect them with self-support groups. Furthermore, because multidisciplinary-approach-focused care is often conducted without families, who do not always accompany the patient, it is necessary to establish an online platform to meet family caregivers' information needs. Healthcare professionals should not assume the information needs according to disease severity or disease duration; rather, they should seek to understand the information needs of family caregivers through a patient-centered approach and provide them with tailored information. Nevertheless, it is important to recognize that family caregivers who are older and less educated need to be more empowered to be involved in information-based caring and that caregivers of patients with bulbar-onset ALS have substantial information needs.

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