

# Case studies of the lives of spouses of people with ALS in South Korea

## – Focusing on the experience of spouses

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“Come on, it would be such a shame for you to die now. It would be so regrettable for you to die after all of this hardship. Stay alive this time and next time die like falling into a peaceful sleep.” (From an interview with a survey participant)

### What is ALS?

In South Korea, “rare intractable diseases” addressed in the Rare Disease Management Act are difficult to treat diseases with a low incidence rate (less than 20,000 people). One such disease is ALS (amyotrophic lateral sclerosis), which leaves patients’ minds clear but attacks their motor neurons (nerves that move the body). Muscular strength gradually declines, muscular atrophy, paralysis, and speech impairments occur, and eventually even breathing becomes difficult as the respiratory muscles weaken. In South Korea it is described as a terrible disease that results in death through respiratory system failure (Hyun-sook Heo, 2013). Modern medicine has not established an effective method of treatment, and there is currently no expectation of a cure. In South Korea, treatment after diagnosis is very expensive. ALS, which causes physical suffering in the patient and imposes financial and psychological burdens on their family members, can be seen as a societal disease (Min-young Lee and Min-hwa Yun, 2010).

### About this research

#### Purpose

The aim of this research is to undertake a detailed analysis and consideration of how their spouses’ lives have changed as the symptoms of South Korean ALS patients progress following their diagnosis.

#### Qualitative case studies

Cases studies were determined to be an appropriate format for this research for the following three reasons: ALS is a rare disease so the number of cases is small, the vivid accounts of the people in question can describe and illuminate aspects of their daily lives that are difficult to grasp through a quantitative approach, and using this method it is possible to attempt a deep and concrete analysis of the participants.

#### Method

- Four spouses of people with ALS who had been on a ventilator for over ten years participated in the survey. When this research began they were trying to establish an organization to provide services addressing ALS patients as subjects, and in December of last year they founded “NPO B.”
- Interview surveys were conducted from May to November of 2017.

#### Analysis

- Based on the surveys, the spouses were divided into seventeen categories grouped into four themes.

Theme	Category
A body in which symptoms appear	<ul style="list-style-type: none"> <li>They thought something was wrong with them so they went to the hospital, but they were told nothing was abnormal</li> <li>They said there was nothing to be done</li> <li>Like a wilted flower</li> <li>It turned out to be ALS</li> </ul>
A body powerless to overcome obstacles on its own	<ul style="list-style-type: none"> <li>Toured the eight provinces of Korea</li> <li>Meeting other patients was their dream</li> <li>They took a lot of strength from religion</li> <li>They could no longer do in the evening what they had been able to do that morning</li> <li>They go beyond limits</li> <li>They have a tracheotomy and go on a ventilator</li> </ul>
A body that breathes with a machine	<ul style="list-style-type: none"> <li>Financial burden</li> <li>A crossroads between life and death</li> <li>Providing nursing care by themselves</li> <li>Systems that alienate them from the government</li> </ul>
Family betrayal and love	<ul style="list-style-type: none"> <li>Being abandoned</li> <li>Because they are husband and wife</li> <li>Companions who support each other (children)</li> </ul>

To begin with, the progress of ALS symptoms was organized into three themes: the period up until ALS was diagnosed (a body in which symptoms appear), the period from confirmation of the disease until tracheotomy and going on a ventilator (a body powerless to overcome obstacles on its own), and the period of living while on a ventilator (a body breathing with a machine). The relationship between the person with ALS and their family (spouse and children) in the midst of this progression was categorized under the theme of “family betrayal and love”.

### Conclusions and recommendations

#### Relationship with parents

The survey participants were bound to their parents by strong relationships of reliance, including expectations and dependence on their financial and psychological support, but they also experienced the bonds between parent and child being severed as the symptoms of the person in question progressed.

#### Relationship with their spouse (with ALS)

Amidst the progress of their spouse’s symptoms, along with experiencing physical, financial, and psychological pain they also experienced their relationship of love and attachment to their spouse becoming deeper and mutual reliance.

#### The dimension of relationships

#### Relationship with children

When their spouse began suffering from ALS, the survey participants had to take responsibility for everything going on in their household. While having to take financial responsibility, at the same time they also experienced having to take on the care of their spouse with ALS and their children. The relationship between the survey participants and their children thus became a relationship of reliance bound together by mutual respect and love.

#### Relationship to society

The survey participants experienced becoming unable to go to work and having their relationships with the people around them break down because of their having to take care of their spouse with ALS.

#### The systemic dimension

The survey participants experienced excessive burdens being placed on spouses by the inadequacy of official support systems and being excluded from social welfare services. People with ALS are people with the most severe degree of disability, possessing a combination of medical treatment and disability support needs, and therefore require round-the-clock nursing care, but finding caregivers to take over these duties is itself difficult, and survey participants were thus trapped in a vicious cycle of having to continue bearing the burden themselves.

My wife is always saying things like this with the letter board. “I love you. Thank you for always [taking care of me]”  
With this everything is over. No matter how painful... Thank you. (From an interview with a survey participant)

#### Policy

#### recommendations

#### • Construct a system of different forms of support for different stages in the progression of ALS symptoms.

- Spouses experience the pain of accepting five degrees of disability as the person with ALS goes through five stages of the disease (diagnosis, difficulty swallowing, tracheotomy, respiratory dysfunction, death).

#### • Supplement the activity support system.

- Establish a flexible nursing care system.

- In South Korea, when a person reaches the age of sixty-five they become eligible for the long-term care insurance system and can no longer utilize welfare services for people with disabilities. Since the amount of care time covered by the long-term care insurance system is less than that covered by welfare services for people with disabilities, flexibility in the system that would allow for the use of the latter is required.

#### Practical

#### recommendations

#### • The training and propagation of family peer counselors.

#### • The formation of self-help groups (action groups formed by and for the spouses of people with ALS).

<Works cited>

• Hyun-sook Heo, 2013. “Quality of Life in Amyotrophic Lateral Sclerosis.” Seoul National University Master’s thesis.

• Min-young Lee and Min-hwa Yun, 2010. “Analysis of elements affecting the socio-psychological wellbeing of people with the rare and intractable.” Journal of Disability and Welfare, 12:123-146.