

## Experiences by Families Supporting Amyotrophic Lateral Sclerosis Patients at Home

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### Abstract

**Aim:** The purpose of this study was to explore to clarify the life and experience of a care giver which care for an Amyotrophic Lateral Sclerosis(ALS) patient at home.

**Methods:** The semi-structured interview was performed by qualitative description research. An object was a care giver who lives at home with the patient.

**Results:** An object is a 60-year-old male, and the wife is diagnosed as ALS three years ago, and has carried the respirator now. 17 subcategories and six categories were extracted from 98 pieces as a result of analysis. Although the husband who lives with an ALS patient, understands that the partner does not get well from illness. During the data analysis, the categories included, "it is hoped that the decline of bodily function can be arrested and live on,"

"my wife's life takes top priority;" "my wife's facial expressions and sign language are taken as words so we can converse;" "the love between the care giving husband and the care receiving wife;" "The actual strain in the body;" "unease about caring for the respirator;" were extracted.

**Conclusion:** Though the husband felt the burden for his body or a life for the wife, the present condition of having had hope and living became clear.

### INTRODUCTION

The rate of Amyotrophic Lateral Sclerosis(ALS) is one in 100,000 people, and in 2009 there were 8,492 afflicted people in Japan. The cause of the disease is unknown, the method of treatment is unestablished, and has been specified by the Japanese government as having no known treatment.

ALS is a nervous disorder (motor neurons) where, when signals from the brain are not transmitted, extremity, throat, and tongue muscles as well as respiratory muscles are distressed. On the contrary the senses, sight and hearing, visceral function, and other involuntary functions of the body are unaffected. The progress of the condition is gradual, and which muscles of the body are affected initially, which muscles will be affected at what speed, and which groups of muscles will be impaired most quickly vary among individuals. Presently, since treatment of the condition is unestablished, so health care professionals have a vital role in

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helping patients "live with the disease" through daily living assistance and emotional support.

ALS patients need twenty-four-hour complete support in order to maintain their lives and to fulfill daily requirements. Support for ALS patients to have "their own personal lifestyle" becomes a problem for family members that live with them. Since their personal wishes must be left to others to fulfill, how the patient and family interact with each other, and how those wishes will be met must be considered and clarified.

Therefore, this study focused the lifestyles and experiences of the main care givers at the patients' homes. The present study aimed to clarify the experiences by Families Supporting Amyotrophic Lateral Sclerosis patients at Home.

## METHODS

The research method employed was a qualitative descriptive study, using a Grounded Theory Approach. Interviews were conducted using semi-structured interviews. The research subjects were family members living with ALS patients, and selection was conducted by making requests to the visiting nurse stations from where the visiting nurses were dispatched to care for the ALS patients. Subjects were informed about and gave their consent to the nature of the research through written documents and verbal explanations.

## RESULTS

### Participant profiles

The subject is a 60 year-old male who lives with an ALS patient. His wife developed ALS 3 years prior to the study and is now attached to a respirator and requires complete care.

### Data collection

An interview was conducted at the patient's home for 60 minutes. The recorded interview was transcribed and analyzed.

### Ethical consideration

The study was approved by the appropriate university, which corroborate its ethical considerations.

### Analysis results

The data analysis results were categorized. There were 98 categories. The data was collected into those with the same or similar meanings, and each one was labeled. 17 subcategories and 6 categories were extracted. The categories included, "it is hoped that the decline of bodily function can be arrested and live on;" "my wife's life takes top priority;" "my wife's facial expressions and sign language are taken as words so we can converse;" "the love between the care giving husband and the care receiving wife;" "the actual strain in the body;" "unease about caring for the respirator;" were extracted. In the following each numbered category is followed by the subcategories.

### It is hoped that the decline of bodily function can be arrested and live on

"We originally thought that lower limb dysfunction was caused by an ovarian tumor, but after the operation

we were told it is ALS and is incurable." "Before she became ill she was walking for exercise, so we thought it was unlikely that her legs would be affected." "Although I have accepted that my wife's disease is incurable, I have hope for a treatment." "I despair over a patient's deteriorating condition with ALS and the available treatment." These are the 4 subcategories for this category.

#### **My wife's life takes top priority**

"I'm not sure how far to continue, but I consider my wife's care to be my job." "Along with lack of sleep, as a husband I have to sacrifice my physical health and lifestyle." These are the 2 subcategories for this category.

#### **My wife's facial expressions and sign language are taken as words so we can converse**

"The husband regards the wife's cues and facial expressions as words." "They send signs and catch meaning on a daily basis to promote mutual understanding." "The letter board becomes stress, but when his wife wants to verbalize something, they use it." "In order that his wife can live comfortably they revise their thoughts. These were the 4 subcategories in this category.

#### **The love between the care giving husband and the care receiving wife**

"In order that his wife does not feel pain, the husband provides thoughtful care." The couple cooperates with each other in care giving." These are the two subcategories in this category.

#### **The actual strain in the body**

"The husband wanted to balance work and house work, but gives his wife's care priority." "The husband becomes ill because of hard work and lack of sleep, so he feels the strain of caregiving." "The husband does not want to put his wife in a potentially dangerous situation." "Other members of the family want to help with care giving, but their lifestyles limit the amount of time they can offer." These are the 4 subcategories in this category.

#### **Unease about caring for the respirator**

I am aware that the respirator is my wife's lifeline." This subcategory was especially true after the earthquake in Japan on March 11, 2011.

## **DISCUSSION**

The conclusions of this study are that the family member who lives with the ALS patient lives giving priority to the lifestyle of the patient. The husband believes that his wife's care is his job, and because they cannot rely on a variety of expensive medicine, he collects a variety of machines, sacrifices his own lifestyle and physical health and manages the care environment. Also, though he knows that his wife's condition is untreatable, he says, "I feel despair when I consider the patient's declining physical condition and the treatment options." "I despair when I consider the choice about a tracheotomy and respirator due to her muscle paralysis."

Table 1. Experience of a family supporting an ALS patient

|   | Category  | Sub Category   | Code  |
|---|---|--|---|
| 1 | It is hoped that the decline of bodily function can be arrested and live on | Lower limb dysfunction was considered to be resulting from a ovarian tumor, but after the surgery, the doctor said "it is incurable" as it is ALS. | Because we are not professional, we thought she has difficulty walking because her ovarian tumor is oppressing her right limbic nerve.<br>It was clearly stated that her leg would not get better with a surgery, because it is ALS.  |
|   |   | Her leg problem was totally unexpected, because she used to go out for a walk before she gets sick.  | She used to walk with a pedometer on her almost everyday.<br>Her leg paralysis and stumbling problem were unexpected.   |
|   |   | The husband understands that his wife will not get better, but he is still seeking hopes in treatment.   | There is only one type of medicine available for this disease, and it is very expensive. This medication can be covered by insurance only when it is officially approved by the metropolitan government.<br>It takes time for the government to approve our application, and this delay may results in her death.   |
|   |   | ALS patients are often driven to despair as they face the reality of function loss and their choice of treatment.                                  | Effective treatment of this disease (ALS) includes tracheotomy and the application of ventilator, but that's pretty much it.  |
|   |   |  |   |
| 2 | My wife's life takes top priority   | I think it is my responsibility to take care of my wife, though I am not really sure how long it may prolong.                                      | I'm the one who needs to take care of my wife as it is our own problem, not anybody else.<br>It is uncertain how long it may prolong.   |
|   |   | The husband is providing care at the expense of his health and time, including his sleeping time.  | Sucking noise is quite audible as she is sleeping next to me. Once I am awakened by the noise, it is difficult to go back to sleep.   |
| 3 | The love between the care giving husband and the care receiving wife        | The husband takes his wife's non-verbal signs and expressions as a verbal message.   | My wife often snarls at me and say whatever she wants.<br>Verbally express things without hesitation.<br>We can tell each other if I am or she is in a bad mood just by looking at each other's face or making an eye contact.  |
|   |   | Communication is accomplished by exchanging signs everyday.  | No speaking ability.<br>Since she cannot push a nurse call button, she has a sensor on her forehead, and every time she wants to call a nurse, she moves her forehead and make a beeping sound.   |
|   |   | A communication board is stressful, and it is used to verbalize my wife's mind.  | She would be fed up with the communication board when her mind is not read easily.<br>My wife usually close her eye and not look at the communication board when she wants to say, "I am tired of it".  |
|   |   | Contributing ideas to to make her life little easier.  | I set up the TV on the wall for her because I felt sorry for her, and now she watches it for almost 24 hours.   |
| 4 | My wife's life takes top priority   | The husband is providing a heartfelt care to his wife everyday so that she would not suffer so much.   | What I feel sad the most about my wife is that she cannot sense any taste nor smell after gastrostomy, so she cannot tell if it is sweet or spicy. It is a sad thing as you can imagine.<br>From my years of experience, I know the gurgle sound is a sign of excessive phlegm, so when I offer to suck the phlegm for her, she winks at me and makes a beeping sound with the ventilator.  |
|   |   | The care is given in such manner that the husband and wife respect and help each other.  | Because she feels uncomfortable breathing when there is excessive saliva in her mouth, she tries to keep it in her mouth like this; however, because she cannot swallow it, she let it drain out from her mouth like this using her tongue.<br>I need to use a sucking device to suck saliva after she let it out from her mouth.   |
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| 5 |   | The husband wanted to be responsible for his office work and house chores, but he gave priority to the care of his wife.                           | I wake up at 6 o'clock, run 4 laps of schoolyard, and go home to do some cleaning, I do all sorts of house chores including bathtub and toilet cleaning, and after that I fix my meal.<br>One day I found my wife caught between a refrigerator and a wall crying, unable to get up. She continued to do her kitchen work until her last minute when she completely lost her ability to move.<br>I've been doing the kitchen work since then. I do my office work, cleaning, kitchen work, and laundry. |
|   |   | He thinks taking care of his wife is too much of a burden, and he became sick because he is tired and not getting enough sleep.                    | I have been taking care of my wife ever since she developed ALS three years ago.<br>I am not in a good condition because I am not getting enough sleep, stressed out and tired.   |
|   |   | He wants his wife to stay away from any potential danger.  | She tried a short day program for three days because our helper advised us so. The helper thought we need some rest.<br>A person who was using a bed next to us had bedsores (around this area), and the leg bone was sticking out.   |
|   |   | Other members of his family also want to help him, but they have their own life and the time they can spend for providing care is limited.         | My daughter takes good care of my wife.<br>Because my daughter is working, she drops by at our house after her work.  |
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|   |   |  |   |
| 6 | Unease about caring for the respirator                                      | He understands that the ventilator is his wife's lifeline.   | I need to stay by her side while she is on the bed in order to make sure the ventilator does not come off.<br>I need to take off the ventilator quite often and suck out her phlegm.<br>I am very nervous.  |
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However, even in the face of this, he says, "In the end there is no treatment." Then, even in the midst of the constant loss and assent, he says, "It is hoped that the decline of bodily function can be arrested and live on," and continues to provide care.

The couple's communication of will, "My wife's facial expressions and sign language are taken as words so we can converse," and in his everyday care there is, "The love between the care giving husband and the care receiving wife," thereby communicating each other's feelings. However the strain of daily care, the sleeplessness, the hard work and stress leave "The actual strain in the body." As a result of the earthquake in Japan on March 11, 2011, the husband feels a strong sense of "Unease about caring for the respirator ."

## CONCLUSION

1. Even though the subject lives with the ALS patient and feels the strain on his health and lifestyle, he believes that caring for the patient is his job.
2. The patient's declining physical ability leads the caregiver to a feeling of hopelessness, and so he lives in hope of a selection of treatment.
3. The husband and wife use cues and facial expressions for communication, maintained constant communication, and keep a loving relationship.

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