論　　文　　要　　旨

ALS 患者の病気の発症と進行が家族の生活にもたらす影響

The influence of Amyotrophic Lateral Sclerosis (ALS) disease trajectory on family members' life

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I. Research Objectives

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that cripples voluntary musculature throughout the body. It lacks an effective treatment method. The onset and progress of ALS affect not only the patients but also their families. However, previous research on families affected by ALS focus on their role as a caregiving unit, and there are comparatively few reports that examine the effects of the condition on the various aspects of a family's life. The purpose of this study was to clarify the effects of ALS onset and progression on family life from interview of bereaved family members of ALS patients.

II. Research Methods

1. Research design: Qualitative-descriptive study using thematic analysis

2. Definition of terminology

In this study, "family" is defined "not merely as individuals that live with the research participant, are married to the research participant, or are related to the participant through marriage, but anyone that the research participant recognizes as family." "Life" and "lifestyle" are defined as "daily activities, attitudes, and movements that are part of the interdependent existences affected by the social, cultural, and geopolitical characteristics of one's living environment, as well as the pathological condition, ADL, values, and habits of the individuals in question; the act of living."

3. Research participants: Bereaved families of ALS patients who died at least one year prior; families that are psychologically stable and are able to speak about their thoughts and feelings.

4. Data collection methods

We requested the members of two ALS patient support groups to participate in our study, and ultimately recruited 10 participants. We conducted 1-2 semi-structured interviews with these individuals according to an interview guide; each interview lasted approximately 90 minutes.

5. Analysis methods

1) Thematic analysis of each case

Thematic analysis in this study was carried out in accordance with "Using thematic analysis in psychology by Braun and Clark (2006)." In our thematic analysis, we sought to not normalize events to the population at large, but rather to preserve the nature of the stories told by our interviewees, and to emphasize the interpretation of the meanings contained therein. We chose to use thematic analysis in this study because ALS is a highly individualized disease, insofar, as the rates of progress of the disease and the parts of affected individuals that become impaired vary considerably from patient to patient. Further, in order to stay true to our broad definition of "life/lifestyle" and to respect the diversity of family structures in the cases we interviewed, we determined that it was important to maintain the distinct nature of the stories in each case, and to analyze the details thereof in their own context.

2) Creation of common themes through the results of thematic analysis of 10 cases

In our thematic analysis of the 10 cases interviewed in this study, after revealing the various effects of ALS onset and progress on family life, we compared cases with one another. To delve deeper into this content, we grouped similar subthemes from each case and created common theme categories.

6. Ethical considerations

This study was carried out with the approval of the Ethics Committee of the Graduate School of Nursing and Welfare, Hokkaido Medical University (approval number 15N028028).

III. Research Results

１． Research participant overview

Ten bereaved family members of ALS patients (nine females, one male) participated in this study. Their relationships to ALS patients were as follows: Five of them were the spouses of ALS patients (four wives, one husband), four were the children of ALS patients, and one was the mother of an ALS patient. Their ages at the time of interview ranged from early the 40s to late 70s (mean age 60.3 years), and the number of years from the death of their patient family member to their interview with us ranged from 6 to 21 years (mean time 11.9 years). The number of years from their patient's diagnosis to death ranged from one to 16 years. Five of the 10 participants' patients were fitted with TPPV devices. Six participants cared for their ALS patients at home, two used both home care and respite care, and two were cared for at a hospital following TPPV fitment. Interview times ranged from 58 to 118 minutes (mean time 91.6 minutes).

2. Analysis Results

After independently carrying out thematic analysis on each of the 10 cases interviewed, we created a total of 83 themes and 287 subthemes. Below, common themes are delineated by ≪≫, categories by {}, and subcategories by []. After grouping and analyzing subthemes obtained from our thematic analyses of these 10 cases, we created six common themes from 124 subcategories and 49 categories: ≪psychological/emotional effects≫, ≪physical effects≫, ≪financial effects≫, ≪self-fulfillment effects≫, ≪relationship effects≫, and ≪effects on children that were minors at ALS onset≫.

The onset and progress of ALS in patients caused ≪physical effects≫ on family members due to care demands, ≪financial effects≫ brought on by the retirement of patients or caregivers, and ≪self-fulfillment effects≫, such as {giving up career continuity}, as well as ≪effects on children that were minors at ALS onset≫. Further, difficulty predicting the progress of ALS led to [anxiety about the future], [feeling of being trapped due to care without an end in sight], and {isolation}. Further, as family members worked to respond to physiological and physical changes in patients caused by notifications about their status and disease progress, they felt negative emotions such as {anxiety} and {exhaustion} due to care demands, which, alongside the process of ALS itself, cornered them and caused them to suffer. However, they were able to simultaneously obtain [a stable daily life pattern through the use of at-home care services] and feel [a sense of emotional relaxation by not expecting perfection from care service], allowing them to experience mental and emotional {peace}, a positive emotion. In these ways, complicated ≪psychological/emotional effects≫ were observed at each stage of ALS progress. Upon examining the aforementioned negative emotions, while some families were affected by these negative emotions even after the patient passed away, other families were able to {overcome} and turn them into positive emotions, like feelings of {achievement} and {relief}. Further, as ALS progressed and patients' ADL abilities declined and their communication abilities became impaired, the bond between patients and their families was

subject to a variety of ≪relationship effects≫. In some families, the relationships worsened. In other families, they worsened temporarily and later improved, and finally, in yet other families, they did not worsen and remained good.

IV. Discussion

In this study, by conducting thematic analyses of 10 cases and analysis of common themes found between them, we were able to descriptively clarify the diverse effects of ALS on families. After considering these effects, we believe that the following forms of support are necessary for the families of patients with ALS. ALS onset and progress in a family member precipitated ≪physical effects≫, ≪financial effects≫, and ≪self-fulfillment effects≫ on their family. These affected elements form the foundation on which patients and their families build their daily lives. Fluctuations in this foundation are directly tied to both patients' and families' quality of life (QOL) and also bring about ≪effects on children that were minors at ALS onset≫. Thus, support that works to reduce the physical burden on families, provides them with financial stability, and safeguards their careers is necessary. Further, because the worsening of relationships between patients and their families as ALS progressed was precipitated by the loss of communication and difficulty in being understood, support that modulates ≪relationship effects≫ among families, such as support that encourages communication within the family, is necessary. Further, support for psychological changes suffered by patients following notification of their status from doctors, and the construction of a follow-up system to support patients and their families is of urgent importance. Moreover, from ALS onset through the progress of the disease, families are assailed by a variety of negative emotions, and some were unable to escape them even after the patient had passed away. This suggests that support that works to mediate ≪psychological/emotional effects≫ even after the patient has passed away is necessary.