An Investigation of Perspectives of Respite Admission Among People Living With Amyotrophic Lateral Sclerosis and the Hospitals That Support Them

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Abstract

Background: Amyotrophic lateral sclerosis is a progressive disease with rapid degeneration. Respite care is an essential service for improving the well-being of both patients with this disease and their family caregivers, but accessibility of respite services is limited. This study investigates perspectives on respite admission among people living with amyotrophic lateral sclerosis and the hospitals supporting them. Method: We conducted semistructured interviews among 3 patients with amyotrophic lateral sclerosis and 12 family members, exploring demographic information and their awareness and experience of respite admission. We also interviewed 16 representatives from hospitals about awareness of and preparation for respite admission for patients with this disease, the role of regional networks for intractable diseases, and knowledge about communication support schemes. Results: We found significant differences in the revised Amyotrophic Lateral Sclerosis Functional Rating Scale between patients who had and had not received respite admission. Qualitative analysis of the data indicated that respite admission was a contributory factor in continuing and stabilizing home care. Limited provision of social services and hospital care quality were barriers to respite admission. Conclusion: Respite admission was essential to continued home care for patients with amyotrophic lateral sclerosis. Severe-stage patients were eligible for respite admission. Its accessibility, however, was limited, especially for patients living in rural areas. Supporting hospitals had limited capacity to respond to patients' needs. Individualized care and communication were internal barriers to respite admission.

Keywords

amyotrophic lateral sclerosis (ALS), respite admission, family caregiver, ongoing home care, service accessibility

Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive disease with rapid degeneration during which ALS patients and their family caregivers suffer physical, emotional, and financial strain.¹−⁶ They require a wide range of health, social, and palliative care services. One essential service is respite care, which improves the well-being of both patients with ALS and family caregivers.⁷−⁹

There has been a “nanbyo care” system in Japan since 1972, in which patients who meet certain criteria and have specific intractable diseases are able to obtain some medical, social, and financial support.¹⁰ Despite this, many unsolved issues remain around the provision of support for those with advanced intractable neurological diseases. These include managing respite admission. There are also considerable regional differences in service provision, because of a shortage of services and uneven distribution of medical and social resources.¹¹−¹³ People living with ALS often find it hard to access support services.⁷,¹⁴,¹⁵

This study was designed to explore discrepancies between the views of ALS patients and hospitals providing support for them in Japan, particularly about respite admissions.

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Materials and Methods

Participants
We explained the study aim to the Mie Prefecture ALS Association Secretariat, which facilitated access to potential participants. We mailed our questionnaire to members, and recruited ALS patients who provided written consent. We conducted semistructured interviews with 3 ALS patients and 12 key family members from September to November 2014. These were mostly by telephone, although 1 participant chose a face-to-face interview. The interviews covered demographic details, health care utilization, awareness, and experience of respite admission, communication ability, and assessment of current ALS severity using the revised ALS Functional Rating Scale (ALSFRS-R).

We also mailed questionnaires to the hospitals in the liaison council of Networking for Patients with Intractable Neurological Diseases in Mie Prefecture. After obtaining written consent, we conducted telephone interviews with hospital representatives between October 2014 and January 2015. These covered awareness and preparation for respite admission for patients with intractable neurological diseases, and roles in the regional network for intractable diseases.

Ethical approval for this study was obtained from the Mie University Hospital Ethics Committee for Clinical Research in September 2014 (approval number 2786, 2787).

Analysis
All statistical analyses used SPSS 20 and significance was based on a t test. Qualitative data were analyzed thematically. Transcripts were read to identify meaningful units, then quotations with similar meanings were categorized into subthemes and themes.

Results
Patients’ Demographic and Characteristics
In December 2014, a total of 144 ALS patients were registered with the prefectural government, 42 of whom participated in the prefectural ALS association. We interviewed 15 of these or their family members (response rate 35.7%).

Table 1 shows the participants’ demographic characteristics. The patients’ mean age was 61.0 years, and 73% were male. The mean time from illness onset to interview was 71.9 months. The mean ALSFRS-R score was 16.2. We classified patients’ communication ability by clinical stage, with 12 patients as stage I, 2 as stage III, and 1 as stage V.

Eleven patients (73%) were in home care settings, 4 of whom had tracheostomy with invasive ventilation (TIV). All of them used home health care services. Among the participants in home care settings, one whose disease was at very early stage was not aware of respite admission. Five participants had undergone respite admission. Another had had respite care arranged but had refused because of the transfer cost. The distance to the respite hospitals was 7 to 65 km. The patient transfer costs were 10 000 to 30 000 yen. All of them were male with their spouses as caregivers.

Within the group in home care settings, we compared the group that had arranged or received respite admission to the group that had not experienced it. The mean ALSFRS-R score was significantly lower (7.3 vs 35.2; P = .00) and the mean disease duration (months) was significantly longer (105 vs 31.6; P = .002) for the respite admission group.

Three patients (20%) were in hospital, one of whom had TIV and another had noninvasive ventilation (NIV). One had TIV in a care facility.

Qualitative Data From People Living With ALS
Two main themes emerged from the interviews with patients and caregivers (Table 2).

Managing to Support Ongoing Home Care. There were some issues that influenced family caregiving, such as other family members’ requirements of care, caregivers’ age, health condition, and working status. Caregivers tended to maximize their use of support services to ease their care load.

Caregivers often mentioned the care burden and desired for a break from caregiving. Caregivers perceived respite services as essential for maintaining home care.

Individual care procedures including positioning and communication were established at each patient’s home, although such care may not be available in hospital. Participants who had undergone respite admission were dissatisfied with the quantity and quality of hospital care. A sense of guilt arose from conflict between the desire for a break from caregiving and the wish to maintain individualized care.

Two patients with relatively early stage (ALSFRS-R: 43 and 34) expected to undergo respite admissions in the future, based on the disease prognosis and family care capacity. Two patients had abandoned home care services because their condition had worsened, and they abandoned home care.

Attempting to Prepare for the Future. People with ALS recognized uncertainty about the illness trajectory, acute deterioration, caregivers’ capacity, and unforeseen issues which influenced their future planning. Some had been kept waiting or refused respite admission to nearby hospitals. Through those experiences, people gained a sense that it was difficult to obtain a hospital bed. They wanted to secure resources to help them cope.
Table 1. Demographic Characteristics of Patients With Amyotrophic Lateral Sclerosis.

| No. | Key Person | Respondent | Age (Years) | Sex | Disease Duration (Months) | ALSFRS-R | Respiration | Respite Admission | Communication Tool | Communication Stage | Setting | Distance to Respite Hospital (km) | Care Management | Visiting Nurse | Visiting Rehabilitation | General Practitioner | Home Care Worker |
|-----|------------|------------|-------------|------|--------------------------|----------|-------------|------------------|-------------------|-------------------|---------|-------------------------------|----------------|--------------|---------------------|---------------------|-----------------|
| 1   | Spouse     | Spouse     | 69          | F    | 73                       | 0        | TIV         | No               | AAC               | I                 | Hospital          | North              | 15                  | No                | No                 | No                 | No             |
| 2   | Spouse     | Spouse     | 47          | M    | 103                      | 0        | TIV         | Yes              | AAC               | I                 | Home              | North              | 37                  | Yes               | Yes               | Yes               | Yes            |
| 3   | Spouse     | Spouse     | 58          | M    | 150                      | 8        | TIV         | Yes              | AAC               | I                 | Home              | Middle             | 65                  | Yes               | Yes               | Yes               | Yes            |
| 4   | Spouse     | Spouse     | 64          | M    | 84                       | 0        | TIV         | Yes              | —                 | V                 | Home              | North              | 19                  | Yes               | Yes               | Yes               | Yes            |
| 5   | Spouse     | Spouse     | 68          | M    | 113                      | 0        | TIV         | Yes              | AAC               | I                 | Home              | South              | 34                  | Yes               | Yes               | Yes               | Yes            |
| 6   | Parent     | Mother in law | 36         | M    | 104                      | 0        | TIV         | No               | AAC               | I                 | Care facility      | North              | 9                   | Yes               | Yes               | No                | Yes            |
| 7   | Spouse     | Spouse     | 72          | M    | 73                       | 3        | NIV         | No               | Body language     | III               | Hospital          | South              | 98                  | No                | No                | No                | No             |
| 8   | Spouse     | Spouse     | 65          | M    | 57                       | 31       | Without support | No               | Verbal            | I                 | Home              | North              | 21                  | Yes               | Yes               | No                | No             |
| 9   | Spouse     | Spouse     | 89          | M    | 129                      | 17       | Without support | Arranged but not used | Body language     | III               | Home              | North              | 15.5                | Yes               | Yes               | No                | Yes            |
| 10  | Spouse     | Patient    | 68          | M    | 40                       | 20       | Without support | No               | Verbal            | I                 | Hospital          | North              | 33                  | No                | No                | No                | No             |
| 11  | Spouse     | Spouse     | 68          | F    | 16                       | 32       | Without support | No               | Verbal            | I                 | Home              | Center             | 11.5                | Yes               | Yes               | No                | No             |
| 12  | Spouse     | Father     | 46          | M    | 22                       | 36       | Without support | No               | Verbal            | I                 | Home              | Center             | 46                  | No                | No                | Yes               | No             |
| 13  | Spouse     | Patient    | 53          | F    | 27                       | 43       | Without support | No               | Verbal            | I                 | Home              | Center             | 13                  | Yes               | Yes               | No                | No             |
| 14  | Spouse     | Patient    | 60          | F    | 36                       | 34       | Without support | No               | Verbal            | I                 | Home              | North              | 10                  | No                | No                | Yes               | No             |
| 15  | Spouse     | Spouse     | 58          | M    | 51                       | 19       | Without support | Yes              | Verbal            | I                 | Home              | Center             | 7                   | Yes               | Yes               | No                | No             |

Abbreviations: F, female; M, male; ALSFRS-R, Amyotrophic Lateral Sclerosis Functional Rating Scale; TIV, tracheostomy with invasive ventilation; NIV, noninvasive ventilation; AAC, augmentative and alternative communication devices.

Communication Stage: I—can communicate in sentences, II—can communicate with one-word answers only, III—can communicate with nonverbal yes/no responses only, IV—can only communicate occasionally because of uncertain yes/no responses, V—cannot communicate by any means.
Hospital Characteristics

Sixteen hospitals out of 19 in the liaison council of Networking for Patients with Intractable Neurological Diseases in Mie Prefecture participated in this study (response rate 84.2%).

Hospital representatives discussed the hospital’s roles in caring for patients with intractable neurological diseases. These included respite admission (13), providing a second opinion (12), managing acute complications of the illness (9), diagnosis (8), long-term admission (7), coordinating regional support (5), educational support (3), and as a trial (2). All hospitals recognized the significance of respite admission, although none regularly scheduled it.

Six acute hospitals with full-time neurologists provided diagnosis, decision-making support, and services for acute complications. They occasionally provided respite admission, but had limited capacity. Three chronic hospitals with full-time neurologists provided respite admission and long-term admission. Four acute hospitals without a neurologist recognized a role in providing respite admission, but had seldom done so. Three chronic hospitals without a neurologist had long-term care wards although they could not manage patients receiving TIV.

Hospital Qualitative Data

Four themes emerged from the hospital interviews (Table 2).

| Theme | Subtheme |
|-------|----------|
| Patients with ALS and their family | Management to support ongoing home care |
| | | Easing the care load |
| | | Conflict between the desire for a break from caregiving and the wish to maintain individualized care |
| | Attempting to prepare for the future |
| | | Recognition that the future is uncertain |
| | | Desire to secure resources to help them cope |
| Hospitals | | Hospitals’ significance in respite admission |
| | | Temporary substitute for family caregivers |
| | | Supporting ongoing home care |
| | | Providing medical care to maintain patient health |
| | | Assessment of patient condition and reconsideration of provision of home care |
| | Current issues and coordination at acute hospitals |
| | | Low priority for acute hospital |
| | | Differences between patients’ expectations and services available at hospital |
| | | Manpower constraints on providing individualized care for patients with ALS during respite admissions |
| | Limited respite facility for patients with ALS at home |
| | | Recognized roles of chronic hospitals |
| | | Made effort to accept respite admissions |
| | Concerns about who leads the care team |
| | | Patient views and decisions may change with time; it is difficult to share information among clinicians and external practitioners |
| | | Poor team approach among medical institutions |
| | | Lack of clarity about leadership of care team |

| Table 2. Overview of Themes and Subthemes About Respite Admission From Patients With Amyotrophic Lateral Sclerosis (ALS) and Hospitals. |
|------------------|-----------------|
| Theme | Subtheme |
| Patients with ALS and their family | Management to support ongoing home care |
| | | Easing the care load |
| | | Conflict between the desire for a break from caregiving and the wish to maintain individualized care |
| | Attempting to prepare for the future |
| | | Recognition that the future is uncertain |
| | | Desire to secure resources to help them cope |
| Hospitals | | Hospitals’ significance in respite admission |
| | | Temporary substitute for family caregivers |
| | | Supporting ongoing home care |
| | | Providing medical care to maintain patient health |
| | | Assessment of patient condition and reconsideration of provision of home care |
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Discussion

This study found that severe-stage longer-term patients with ALS were generally able to access respite admission, although the sample size was small. People with ALS face
uncertainty and therefore try to manage it. Respite admission is an important coping strategy to help manage and maintain ongoing home care but both quantitative and qualitative service provision was insufficient.

All the hospitals in this study understood the significance of respite admission, although acute hospitals in particular found it difficult to provide individualized care for ALS patients. There was a mismatch between patient expectations and hospitals’ capacity, and acute hospitals limited respite admissions. A small number of chronic hospitals therefore accounted for the majority of such admissions. Distance to service resulted in high transfer costs, especially for patients in rural areas. In this study, quantitative data were analyzed using data about homecare settings. We used qualitative data from all participants, which covered difficulty of caregiving and service access at home. These may be equivalent to “abandoned home care.”

Home care for patients with ALS often decreases as the disease progresses. This results in a greater care burden and affects patients’ future planning. Respite admission is therefore important for severe-stage ALS patients. Patients and family caregivers expressed dissatisfaction with care during respite admissions. Caregivers were often afraid to discuss respite admission with patients. In this study, 2 patients with early-stage disease expected to need respite admission. This suggests that early discussion about respite facilitate will future planning.

Several professionals within hospitals and in the community are involved in managing care for ALS patients. These patients have a wide range of care needs and different ethical issues arise at different disease stages. Professionals mentioned problems working across organizations. Patients’ needs and decisions may change over time, and no professionals are prepared to assume overall long-term responsibility, but gaps in information and communication among health professionals lead to disruption of services. Coordination of cross-boundary working is necessary in ALS care to promote cooperation within the care team and stable care at home.

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