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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,[16] 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,[17] 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.

			Patient										Patient Service Use				
									Communication								
No.	Key Person	Respondent	Age (Years)	Sex	Disease Duration (Months)	ALSFRS-R	Respiration	Respite Admission	Tool	Stage[a]	Setting	Location	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	No
2	Spouse	Spouse	47	M	103	0	TIV	Yes	AAC	I	Home	North	37	Yes	Yes	Yes	Yes	Yes
3	Spouse	Spouse	58	M	150	8	TIV	Yes	AAC	I	Home	Middle	65	Yes	Yes	Yes	Yes	Yes
4	Spouse	Spouse	64	M	84	0	TIV	Yes	—	V	Home	North	19	Yes	Yes	Yes	Yes	Yes
5	Spouse	Spouse	68	M	113	0	TIV	Yes	AAC	I	Home	South	34	Yes	Yes	Yes	Yes	Yes
6	Parent	Mother in law	36	M	104	0	TIV	No	AAC	I	Care facility	North	9	Yes	Yes	No	No	Yes
7	Spouse	Spouse	72	M	73	3	NIV	No	Body language	III	Hospital	South	98	No	No	No	No	No
8	Spouse	Spouse	65	M	57	31	Without support	No	Verbal	I	Home	North	21	Yes	Yes	No	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	Yes
10	Spouse	Patient	68	M	40	20	Without support	No	Verbal	I	Hospital	North	33	No	No	No	No	No
11	Spouse	Spouse	68	F	16	32	Without support	No	Verbal	I	Home	Center	11.5	Yes	Yes	Yes	No	No
12	Spouse	Father	46	M	22	36	Without support	No	Verbal	I	Home	Center	46	No	No	Yes	No	No
13	Spouse	Patient	53	F	27	43	Without support	No	Verbal	I	Home	Center	13	Yes	Yes	Yes	No	No
14	Spouse	Patient	60	F	36	34	Without support	No	Verbal	I	Home	North	10	No	No	Yes	No	No
15	Spouse	Spouse	58	M	51	19	Without support	Yes	Verbal	I	Home	Center	7	Yes	Yes	No	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.
[a]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.

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
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

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).

Hospitals' Significance in Respite Admission. Hospitals viewed respite admission as a temporary break for caregivers and a factor supporting ongoing home care. Respite admission might also be an opportunity to assess a patient's condition and reconsider home care provision.

Current Issues and Coordination at Acute Hospitals. Acute hospitals prioritized acute care over community medicine and safety management. Hospital representatives commented, "It's not easy to care simultaneously for acute patients and chronic patients with intractable diseases." Some hospitals limited respite admissions to primary patients.

Limited Respite Bed for Patients With ALS. Two chronic hospitals showed actively accepted respite admissions. Respite requests from across the prefecture were therefore concentrated on those hospitals despite limited beds.

Concerns About Who Led the Care Team. Multiple health professionals were involved in caring for patients with ALS, and most tended to feel ambiguous about their roles within the team.

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[1] and therefore try to manage it.[18] 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.[8,11,13,19-21] This results in a greater care burden[4,22] and affects patients' future planning.[23,24] 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.[18,21,25] 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,[24] but gaps in information and communication among health professionals lead to disruption of services.[26] Coordination of cross-boundary working is necessary in ALS care to promote cooperation within the care team and stable care at home.

Declaration of Conflicting Interests

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