

Original

Nursing support for a patient with an incurable disease and her family, with consideration of their life stage

— Based on support provided for a spinocerebellar degeneration patient and her family during home care —

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Abstract

With prolonged treatment, home-care patients and caregivers experience an age-related decline in physical strength, economic change, and a change in the family structure and relationships. Nurses are required to cope with the needs of the family appropriately in accordance with the changes and stages of the home-care patients and their families. In particular, patients with an incurable neurological disease suffer marked damage that impacts their swallowing and respiratory functions associated with disease progression. Thus, careful observation and support tailored to each stage are necessary. This paper focuses on long-term support for a patient with an incurable disease and discusses nursing tailored to her family's life stage.

Key words : spinocerebellar degeneration, family support, life stage, long-term support

I Introduction

Medical conditions of many patients with an incurable disease worsen in the long-term, which also has a marked effect on their family members during that period. In the present study, we describe nursing support for a patient with an incurable neurological disease for over 10 years with the consideration of the life of a family member who was taking care of her, and we reviewed the style of long-term support for the future.

II Methods

1. Study Design: Case Study
2. Subjects: A female home-care patient with spinocerebellar degeneration who had been using a home care nursing service for 9 years, with her husband as the primary care giver.

3. The study period: August 2012—March 2013
4. Data collection method:
 - 1) Collection of information from medical records and interviews with nurses in charge of the home-care patient.
 - 2) A semi-structured interview was conducted with her husband who was providing home care for the patient to inquire about the recuperation.

III Ethical considerations

The study subjects were informed that a report would be compiled for research purposes, the method of investigation, and presentation at an academic meeting. They were also informed that the research would be conducted without using their names and that their refusal to participate would not result in any disadvantage. Their consent was then obtained. The study was con-

ducted with the approval of the ethical review board of an organization with which the researchers were affiliated.

IV Case overview

The home-care patient was a 77-year-old female. She had been diagnosed with spinocerebellar degeneration in 2001 (at the age of 64). At the time of the diagnosis, she was able to walk by herself. However, as the condition progressed, she gradually had difficulty walking and swallowing. The main caregiver was her husband (80 years of age; he was 67 years old at the time of his wife's disease onset). The couple had a daughter who lived close to them. Because the daughter had a young child, it was difficult for her to participate in caring for her mother. The patient's husband cared for his wife by himself. Her husband actively cared for her and mostly did everything by himself. However, his physical strength decreased with advancing age.

V Results

On the basis of the results of medical records and nurses' interviews, the course of the nurses' visiting care for the couple over 10 years was divided into three stages. The status of support in each stage is shown in Table 1 below.

In the first stage, the patient's medical condition was not very serious. Because her husband was in his 60s and still had favorable strength, he was able to actively participate in his wife's care-taking. The role of visiting nurses was to give guidance to the couple to maintain their lives. In the second stage, her condition deteriorated.

Thus, treatment and care were required for life support, and informed consent was obtained for these treatments. At this stage, family members had to make an important decision regarding the patient's life support.

Therefore, the psychological support for the family became an issue for visiting nurses. In the third stage, the husband could no longer take sufficient care of his wife because he was in his 80s and his physical strength had declined. Therefore, it became necessary to introduce nursing and care services for the maintenance of the husband's health. At this stage, it became possible to obtain the cooperation of their daughter who had finished the most intensive period of child care. Thus, a care system was successfully established that included their daughter.

VI Discussion

In the early phase of the disease, the husband was 67 years old and his motivation for care and physical strength were high. However, as his wife's medical condition progressed, the burden of care increased and the husband's physical strength conversely decreased. Thus, it was necessary to increase and expand the support with the progression of the patient's condition. In addition, approximately 10 years after the onset of her illness, the husband's physical strength markedly decreased; thus, the focus of support shifted to obtaining cooperation from family members and the husband's health care.

As it is with individuals, there are developmental stages for the family as a whole (Okado, 1991). One of the biggest problems with pro-

Table 1 Support tailored to the pathological stages of a home-care patient with spinocerebellar degeneration

<p>1. First stage (from the onset to third year) : The patient's medical condition was stable. The husband's motivation and physical strength were relatively high in this stage. ⇒ Pathology observation and care guidance</p>
<p>2. Second stage (from the fourth to ninth year) : Due to the decline in the patient's ADL, worsened respiratory status, and deterioration of the swallowing function, life sustaining medical treatment and care, including an air mattress, a ventilator, and gastrostomy, were required. The care burden on her husband increased in this stage. ⇒ Proposal and introduction of treatment for life support and medical equipment ⇒ Psychological support for the patient and her husband ⇒ Establishment of system for sudden deterioration ⇒ Guidance on suction to family members ⇒ Increase and expansion of support to reduce care burden</p>
<p>3. Third stage (from the tenth to thirteenth year) : Due to the reduction of the caregiver's (husband) strength, support for the husband became necessary. ⇒ Observation of the pathology of the husband ⇒ Request for their daughter to cooperate in care ⇒ Certification of Need for Long-Term Care for the husband and use of a day service ⇒ Establishment of support system for the couple</p>

longed care is a decline of the caregiver's physical strength. In this case, the introduction of appropriate care equipment, modification of care technology, and reconstruction of the care system are a top priority with the progression of the patient's medical condition. In this family's case, the caregiver (husband) entered old age and it became difficult to accept new developments. During the time when his physical strength started to decline, it was important for the nursing care to be tailored according to changes in the husband's thoughts and physical strength. At the time of her mother's disease onset, the daughter had a young child and could not participate in the care of her mother. However, as her child grew, she was able to shift her time from parenting to caring for her parents. In such a case, child support for the daughter was required to allow her the time to participate in parental care.

The results indicated that medical assistance

tailored to the life stage of the entire family is important in long-term support, rather than only focusing on the change in condition of the home-care patient.

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