Case Report: The Development of a Feeding Harness for an ALS Patient

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In treating patients with amyotrophic lateral sclerosis occupational therapists face an ever-changing disability for which they must select a wide range of assistive devices to maximize function in performance of activities of daily living. This case report emphasizes the significance of the patient's contribution in the fabrication of equipment. The success of the feeding harness described depended as much on the process of its creation as on the enhanced function it gave the patient. The harness offered the patient a sense of hope and helpfulness in the face of a relentlessly progressive disease.

Patients with amyotrophic lateral sclerosis (ALS) exhibit individual variation in the ordering of symptoms and in the rate of disease progression. However, a number of functional profiles commonly occur. When evaluating large numbers of individuals at regular intervals as the disease progresses, patterns of weakness become evident. These functional profiles present some interesting challenges to the occupational therapist who is concerned with providing, recommending, and fabricating assistive devices. The therapist must have a thorough knowledge of the specific progression of ALS in an individual patient, and a close partnership of patient and therapist is also essential. This case report describes a functional profile characteristic of ALS and the development of a feeding device designed by the patient and implemented by the occupational therapist. It illustrates the importance of incorporating the patient's ideas, interest, and skills into the treatment plan to achieve the occupational therapy goals for the patient's psychological and functional needs.

Patient Data

T.M., a 51-year-old retired fireman, was found to have ALS 2 months following the initial onset of symptoms, which included "twitching" and occasional cramping of the fingers in his right upper extremity. Two months after diagnosis he was seen at an outpatient ALS clinic staffed by a neurologist, physiatrist, nurse, social worker, occupational therapist, and physical therapist. The patient was referred to speech therapy for treatment of his mild dysarthria with hypernasality and was to be followed by the social worker on a regular basis to deal with his illness-related depression. The occupational therapist performed a baseline evaluation to determine immediate and long-term needs for assistive devices and to establish a supportive relationship that would

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The harness he designed for himself used a simple pulley action to enable his relatively strong elbow extensors in one upper extremity to reciprocally assist his weak elbow flexors in the opposite extremity. This action would bring either hand to his mouth for feeding.

include the patient’s involvement in his own care.

During initial evaluation, a brief manual muscle test was performed. T.M. was noted to have normal strength in his upper extremities with the exception of good shoulder flexion, good plus elbow flexion, and good finger abduction and extension. Grasp and pinch measured by the Martin vigorimeter were found to be minimally impaired. He demonstrated sufficient hand function in managing such activities as fine fastening, writing, and turning keys.

T.M. continued to be followed by the occupational therapist during his regular 3-month visits to the ALS clinic (during each visit he was to be seen by the entire clinic team). Over a period of 2 years, fine hand function and shoulder strength decreased to the point that he required the use of assistive devices for writing and feeding. At that time his social worker noted that “he has devised gadgets to enhance his functioning, which reinforces a sense of hope and prevents him from dwelling on his limitations.”

On his visit to the ALS clinic 2½ years after the symptoms initially occurred, strength in his shoulder abductors and flexors had diminished and were in the poor range. However, elevation remained good, elbow flexion fair minus, and elbow extension good. T.M. remained able to feed himself by using trunk movement to compensate for proximal upper extremity weakness. He relied on finger adduction to hold utensils because he was no longer able to use built-up handles. Family members were gradually assisting him with dressing, but T.M. was shaving himself independently by using pulleys and a portable mirror. He continued to be fully ambulatory and to take public transit to attend the clinic.

Functional Profile

T.M. presented a picture of severe bilateral upper extremity weakness with elbow extension stronger than elbow flexion. He had normal function of his neck, trunk, and lower extremities. Over a period of 2½ years, he demonstrated a moderate rate of progression of weakness, with a predominance of lower motor neuron signs (i.e., weakness and atrophy) over upper motor neuron signs. It was anticipated that at a certain point he would be unable to bring either hand to his mouth for feeding.

Development of a Feeding Harness

Commercially available feeding devices, including balanced forearm orthoses, overhead suspension slings, and electronic feeders, are primarily designed for use with a wheelchair. They did not provide sufficient portability for T.M.

T.M. was seen in the occupational therapy department for four weekly sessions to work out his design and construction of a feeding harness. The harness would use a simple pulley action to enable his relatively strong elbow extensors in one upper extremity to reciprocally assist his weak elbow flexors in the opposite extremity. This action would bring either hand to his mouth for feeding.

T.M. had used a palatal lift to improve his articulation, but with ongoing progression of the disease, his speech was now nearly unintelligible. He was barely able to draw a rough diagram of his design conception with his nondominant left hand. The therapist demonstrated the handling techniques used with thermoplastic splinting material to T.M. and his son. He was anxious to get the device fabricated as soon as possible, and his family asked to assist in the process. They were gradually adjusting to the patient’s increasing dependency on them, and they shared his concern about future changes in function. T.M. was unable to manipulate the splinting material. Sending the material home with the patient so that his wife and son could help with the fabrication of the shoulder shell was part of the process of preparing the caregivers for their role of aiding the ALS patient. This action was also an expedient solution in a rapidly progressive disease that helped reduce the number of visits to the occupational therapy department.

At his next visit T.M. returned with a feeding harness, a thermoplastic form that rested on both shoulders. At the back of his neck was an extension that held a piece
of tubing (from an incentive spirometer that had been used by one of his sons). Cotton cord was threaded through this tubing and extended along each arm, attaching to his hands via a loop.

On subsequent visits the harness was modified by the therapist to fit more closely to the contour of his shoulders, perforated thermoplastic was used to decrease weight and improve ventilation, a flexible ¼ in. diameter plastic drinking straw was substituted for the spirometer tubing, and nylon cord was used to replace the cotton cord to improve pulley action. Following the patient's instructions, the therapist constructed leather cuffs with thumb loops. The nylon cord was attached to the cuff just below the carpometacarpal joint of the thumb. Six months later underarm straps were added to anchor the harness more securely on T.M.'s shoulders and to reduce the flexibility of the support that held the plastic straw and nylon cord.

Treatment Results

T.M. was able to use the feeding harness for approximately 7 months in public while socializing with his fellow firefighters and when eating at home (see Figure 1). He brought it with him to a weekly patient group to share his idea with other patients. A disadvantage of the harness was that the materials used did not sufficiently dissipate heat for him to wear it for more than a limited period at a time. As his ability to use it decreased, T.M., anticipating future needs, worked on designing an “intravenous drinking device” to enable himself to sip liquids at will.

Summary and Discussion

ALS is a progressive disease with increasing muscle weakness that creates a series of activities of daily living problems. Just as a patient and his or her family resolve one problem, another occurs. These functional changes require constant emotional and physical adaptation. T.M. was able to use his own creativity and exert personal control over his life by designing his own assistive devices. His family was closely involved and able to share in his pride in designing a unique piece of equipment that was not only beneficial to him but also to others with ALS. The occupational therapist served as a catalyst by honoring and capitalizing on T.M.'s interests and ingenuity. By allowing T.M. active participation and by providing emotional support, the therapist enabled the patient to maintain his self-esteem and grow as a person just at the point in his life when he was dealing with a devastating, debilitating, terminal disease. The feeding harness developed by T.M. may be seen as a prototype device. Its overall success in meeting his needs was in large part due to the partnership of patient and therapist.

RELATED READINGS

Takai VL: ADL and adaptive equipment for ALS patients. Phys Disabil Special Interest Section Newsletter 6(2):1, 1983