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Functional outcomes after home-based rehabilitation for heroin-induced spongiform leukoencephalopathy[☆]

Xuhong Li¹, Liming Deng¹, Bin Ye²

¹Department of Rehabilitation, Third Xiangya Hospital of Central South University, Changsha 410013, Hunan Province, China
²Department of Radiology, Third Xiangya Hospital of Central South University, Changsha 410013, Hunan Province, China

Abstract

A 22-year-old man with a 2-year history of heroin vapor inhalation developed spongiform leukoencephalopathy and underwent clinical and home-based rehabilitative treatments. Activities of daily living were measured using the Functional Independence Measure at discharge and at 6, 12, and 24 months after discharge. His neurological symptoms gradually disappeared with rehabilitative treatment, and the functional scale scores increased from 55 on admission to 105 at 24 months after discharge. These results suggest that home-based rehabilitation was effective in ameliorating the pathology and improving activities of daily living in this patient with heroin-induced spongiform leukoencephalopathy.

Key Words: home-based rehabilitation; heroin-induced leukoencephalopathy; functional independence measures

Abbreviations: HSLE, heroin-induced spongiform leukoencephalopathy; CSF, cerebrospinal fluid; FIM, Functional Independence Measure

Xuhong Li[☆], M.D., Attending physician, Department of Rehabilitation, Third Xiangya Hospital of Central South University, Changsha 410013, Hunan Province, China

Corresponding author: Bin Ye, Ph.D., Associate professor, Department of Radiology, Third Xiangya Hospital of Central South University, Changsha 410013, Hunan Province, China
yebin9992003@163.com

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INTRODUCTION

Heroin-induced spongiform leukoencephalopathy (HSLE) usually affects young people and is characterized pathologically by vacuolar degeneration as a result of primary damage to myelin. The spongiform vacuolar degeneration is closely associated with the severity of demyelination in the cerebral white matter^[1-2]. Most survivors of HSLE have courses complicated by severe and complex disabilities affecting their physical, cognitive, and behavioral and social functions. Rehabilitation is an effective and important process for improving functional outcomes after neurological damage^[3-4]. Disabilities caused by HSLE have enduring social and economic consequences, partly because of the burden on the healthcare system and dependency on carers for physical and financial assistance. Economic limitations on the duration of rehabilitative therapies continue to increase. However, it is important to address the management of the sequelae of HSLE during the long-term chronic phase, not just in the acute and immediate sub-acute settings. Strategies to facilitate long-term outcomes and maximize an individual's capabilities therefore need to be developed.

In China, the concept of social work in rehabilitation teams is relatively recent. Caregivers who can deliver rehabilitation services play an important role in providing home-based rehabilitation, but long-term follow-up studies of patients with HSLE are lacking. The present case study investigated the feasibility and functional outcomes of home-based rehabilitation for HSLE.

CASE REPORT

A 22-year-old unresponsive man presented at the Emergency Department of the Third Xiangya Hospital of Central South University, China with a Glasgow coma scale score of 5 (out of a possible 15). He had no fever, headache or vomiting. The initial differential diagnoses included intracranial infection, adrenoleukodystrophy, progressive multifocal leukoencephalopathy, and toxic exposure. The results of electrolyte, hematology, human immunodeficiency virus and *Treponema pallidum* tests were all negative. He had not received any vaccinations. Cerebrospinal fluid (CSF) examination, including cytological analysis, was also normal. The results of additional investigations, including serological tests for infective agents, were also negative, as were CSF viral and bacterial cultures. Toxicology

screening was positive for morphine and diphenhydramine. He was normotensive. A diagnosis of spongiform leukoencephalopathy should be considered in a patient with acute cerebral signs and a reported history of heated heroin vapor inhalation and intravenous injection for 2 years. A definite diagnosis of HSLE was made by identification of typical brain magnetic resonance imaging (MRI) findings of bilateral symmetric high-signal lesions in the white matter of the cerebrum on T1- and T2-weighted images, compatible with toxic leukoencephalopathy involving the frontal, parietal and occipital, and temporal lobes (Siemens 1.5T MRI machine; Figure 1).

The patient underwent supportive treatment (coenzyme Q and vitamin supplements), hyperbaric oxygen therapy

(three 10-day courses of 60 minute pure oxygen at 2.4 atmospheres absolute per day) and a period of in-hospital rehabilitation. Over the next 8 days following admission, the patient developed dyspnea with sputum and received a tracheotomy. In-hospital rehabilitation could not be resumed until the patient was medically stable. During the course of his personalized neurorehabilitation, most of the patient's cognitive dysfunctions resolved. One month later, he could sit with help, and made rapid daily progress in his ability to produce sensible and grammatically correct sentences, despite his spasticity. However, he continued to suffer from depressed mood, low functional activity status, and lack of social support, associated with poorer functional outcomes.

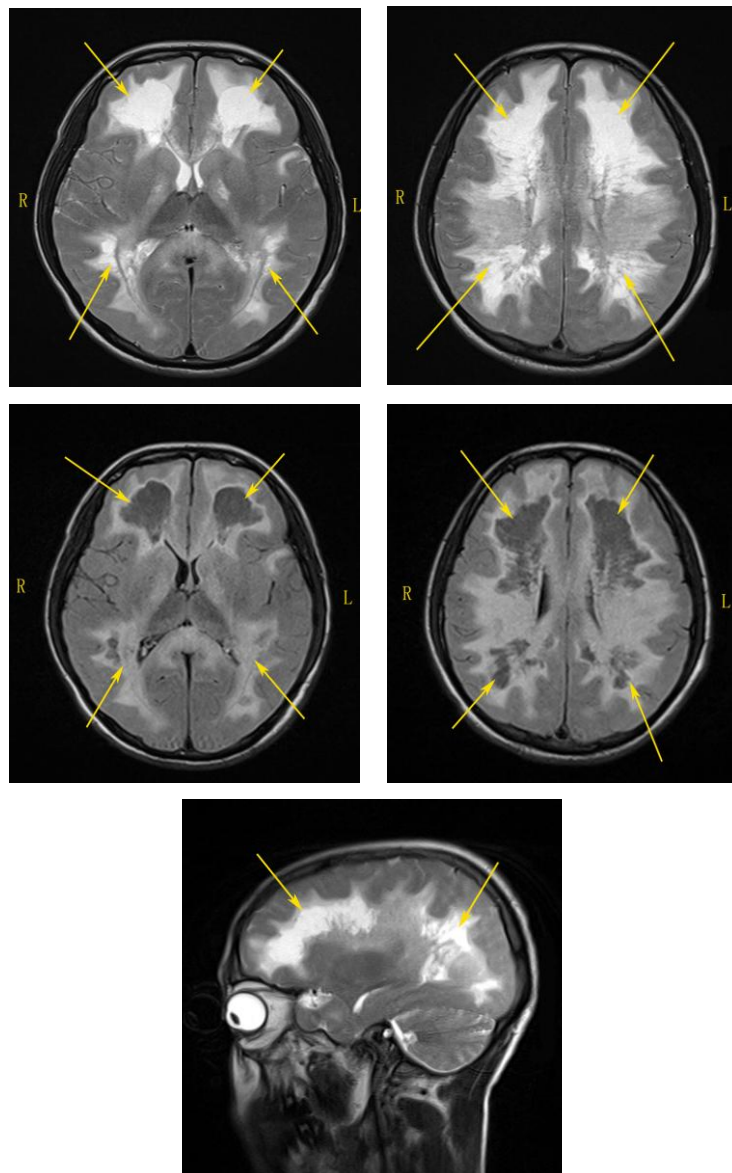


Figure 1 Typical brain magnetic resonance images in a patient with heroin-induced spongiform leukoencephalopathy on admission. Arrows show bilateral symmetric high-signal lesions in the white matter of the cerebrum on T1- and T2-weighted images. R: Right; L: left.

The option of home-based rehabilitation may help to increase participation for some patients. At the beginning of the inpatient rehabilitation period, the caregiver received intensive skill support offered by members of the hospital medical specialist staff – rehabilitation physicians, physiotherapists, psychologists, and other professionals. These specialists visited the patient's home weekly or monthly and trained the patient and his caregiver to deliver a complete home rehabilitation program of physiotherapy and occupational therapy twice a day, for 1 hour each time. The program included mobilization, selective movements, sitting, standing, sensory and visual perceptual training and cognition, transfers, ambulatory activities, personal activities of daily living, domestic activities of daily living, and leisure-

and work-related activities. The patient's neurological symptoms gradually disappeared after receiving home-based rehabilitation, and he made significant functional improvements. Functional Independence Measure (FIM)^[5] scores range from 18 (completely dependent) to 126 (completely independent). The patient's score measured after 2-year follow-up had improved significantly (105), compared to his scores at discharge (55) and at 6 months (75) and 1 year (96) after discharge. He was well, and was able to return a community job for long-term living. His family also had a much better chance of returning to their pre-injury lifestyle. Repeated MRI at 12 months confirmed almost complete resolution of the bilateral abnormalities in the cerebral white matter^[6] (Figure 2).

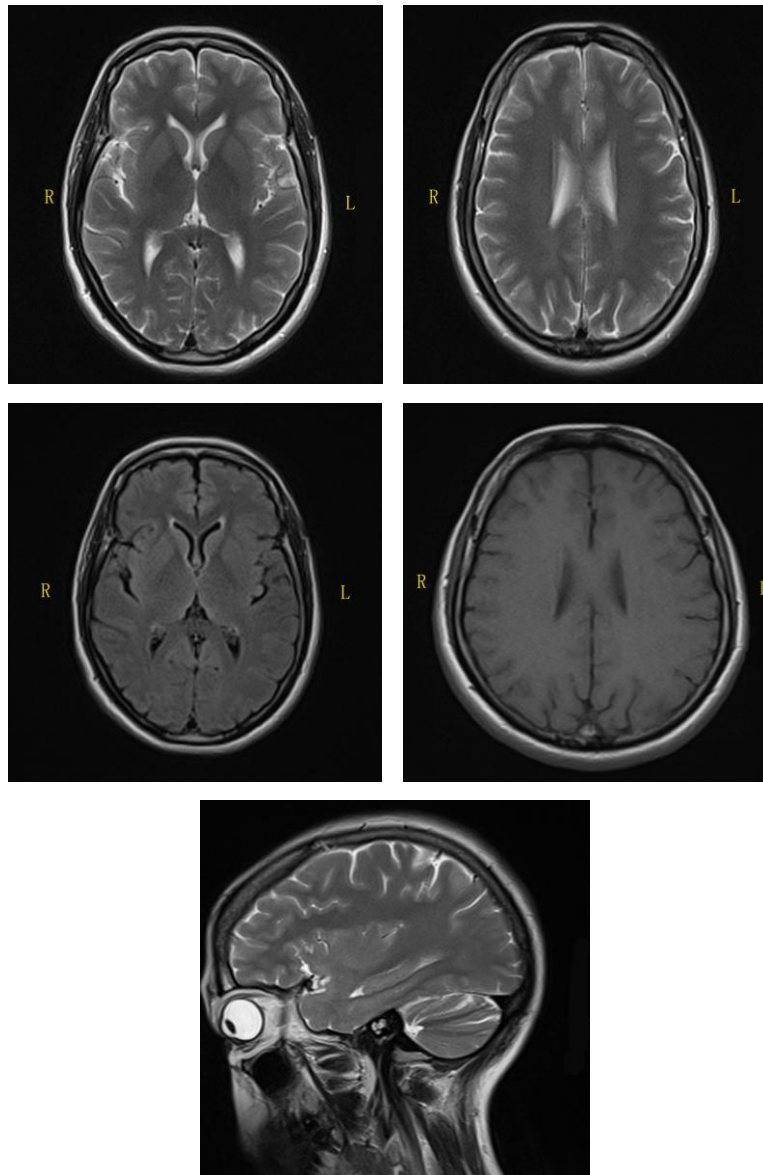


Figure 2 Brain magnetic resonance images of a patient with heroin-induced spongiform leukoencephalopathy following 12 months of home-based rehabilitation demonstrating almost complete resolution of bilateral abnormalities in the cerebral white matter. R: Right; L: left.

DISCUSSION

The original description of leukoencephalopathy in association with heroin inhalation was proposed by Wolters in 1982^[7]. Subsequent and sporadic cases have been described across China, Canada, the United States and elsewhere^[8-10]. The main pathologic features of HSLE are unique, characterized by demyelination and vacuole formation. However, its exact pathogenesis remains poorly understood. There are many etiologies of leukoencephalopathy, including genetic disorders, cerebrovascular disease, eclampsia and toxic exposures. The clinical presentation of HSLE varies widely and the clinical manifestations of the disease reflect the areas of the brain involved in the disease process. Clinical features range from inattention, forgetfulness and personality changes, to dysarthria, ataxia, dementia, coma and death. With increasing numbers of people taking drugs, the incidence of spongiform leukoencephalopathy is rising gradually. The illness lacks any curative treatment, highlighting the need for further investigations. The total reported incidence of HSLE in six cities in China was 3.16 per thousand^[7, 11]. HSLE, though rare, can cause serious, long-term disability. Moreover, it is associated with long-term medical expenses resulting from nursing home and ambulatory care, as well as indirect expenditure from lost earnings and informal care.

This case report indicates that home-based rehabilitation is an effective strategy for further assisting the patient and their caregiver to re-establish their lives in the community after HSLE. Home-based rehabilitation has not been considered previously in China because of a lack of professional guidance, and community-based rehabilitation is still under development^[12]. Home-based rehabilitation mainly focuses on cognitive, behavioral and motivational impairments, physical work capacity and endurance aspects, such as strength and endurance training, and aerobic exercise for stroke, traumatic brain injury pulmonary, and cardiac rehabilitation^[13].

Databases reporting the results of home-based rehabilitation interventions have indicated promising results in improving the health of stroke patients and in obtaining high levels of satisfaction^[14]. Home-based rehabilitation for survivors of HSLE is thus possible, and effective, safe, and accessible training modalities for home-based rehabilitation may offer an important treatment for patients with HSLE. Physicians, therapists, and nursing staff responsible for rehabilitation practices should address this issue, not only during inpatient rehabilitation, but also after discharge, by promoting and supporting home-based exercise opportunities. The frequency and intensity of rehabilitation need to be increased to allow patients to achieve the energy levels and vigor necessary for participation in physical activity, both during rehabilitation and after discharge. Significant improvements in several quality of life indices, including

physical function, mental health, body pain, vitality, and social function, were also demonstrated, and these improvements were maintained during follow-up. Balance training seems to be effective in improving the activities of daily life, gait velocity and balance control, as well as in reducing the risks of falls. This patient received baclofen, which, at a dose of approximately 300 µg per day, consistently diminishes or alleviates muscle spasms in both the upper and lower extremities. Long-term care for patients with HSLE places caregivers under considerable emotional, financial, and physical stress. However, to the best of our knowledge, psychological interventions aimed at this specific patient population remain under-developed. Home-based rehabilitation programs for HSLE represent an effective and relatively low-cost complement to hospital-based rehabilitation and should be considered for stable patients less likely to access or adhere to hospital-based services. Although neuroimaging has played a role in the acute management of brain disease, its use as a tool for understanding and predicting long-term brain-behavior relationships has been limited^[15]. However, the chronic sequelae of cerebral abnormalities in this patient gradually disappeared before successful functional recovery, in line with the ongoing rehabilitation effort. Upon returning home, further home-based rehabilitation resources may be required to maximize recovery and prevent deterioration. There is therefore a need for interventions to improve physical impairments and disabilities, and to increase health status, participation, and FIM. The present case report demonstrates that prolonged home-based rehabilitation may have significant benefits for patients with HSLE, and that cerebral white matter abnormalities can slowly regress. This study also highlights the role of rehabilitation in enhancing the FIM score in HSLE patients. This pattern of home-based rehabilitation has not been reported previously, and may represent a valuable new strategy for treating this group of patients. However, further research is needed to confirm these findings.

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Author contributions: Xuhong Li was responsible for the study proposal, design, data acquisition and writing of the manuscript. Bin Ye was responsible for validation of the study, and also served as the corresponding author. Liming Deng conducted experiments.

Conflicts of interest: None declared.

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