

Investigation and intervention on the psychological status of families with Hepatolenticular Degeneration children

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Abstract: Objective To investigate the psychological status of family with Wilson's disease children, interventions to alleviate chronic sorrow of their families. **Methods** 25 children with Wilson's disease were randomly divided into 13 control group parents, and 12 observation group, was evaluated for both groups were applied ABQ parents of children with mental status; the control group received routine care in the observation group to the targeted group intervention and individual intervention, 3 months after evaluation by the scale effect. **Results** The parents of children with the observation group questionnaire sadness, anger, pain and the total degree of improvement was significantly better than the control group (all $P < 0.05$). **Conclusion** Presence of chronic sorrow the family in children with Wilson's disease, early assessment and implementation of targeted intervention, will help ease psychological burden of parents of children with epilepsy to reduce their family of chronic sorrow.

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1. Introduction

Hepatolenticular Degeneration (HLD), also known as Wilson disease (WD) is an autosomal recessive copper metabolism disorder, the worldwide incidence of it is 1/100 000 to 1/30 000^[1]. The pathogenic gene carrier of the disease is about 1/90. It has a higher prevalence in the Chinese population mainly occurs in adolescents. The main clinical manifestations are characterized by tremors, muscle rigidity, and unclear articulation, mental disorders and cirrhosis of the liver. HLD is one of the few treatable genetic diseases of the nervous system; the key is early diagnosis, early treatment, late diagnosis or inappropriate treatment lead to disability or even death.

However, in clinical care, we found that most parents can not correctly treat the pathological behavior of the children. The lack of disease-related knowledge leads to incorrect responses, and thus can not provide a good family support to the children, impairs of treatment outcome and quality of life of the children. Olshansky^[2] proposed the concept of chronic sorrow, a cycle of recurrent pain or sorrow of parents or caregivers, which can occur in different periods with children with severe or chronic disease. If the sorrow last more than 2 to 3 months, it becomes chronic sorrow. In this study, we investigated and analyzed the psychological condition of the families of HLD children and take specific care measures to improve the psychological status of the parents and caregivers.

Object and Methods

1.1 Object 25 diagnosed HLD cases in the neurology

clinic out-patient and ward of our hospital from July 2006 to July 2010, 19 males and 6 females, aged 2 to 19 years, the average age is 9.3 years. Three were brothers in the 25 cases. The first symptoms, in 13 cases (52.0%) were physical disabilities, in 6 cases (24.0%) were mental disorders, in 6 cases (24.0%) were liver damage. The age of onset was 17 years of age, duration ≥ 1 month. Among the 25 parents, 11 were mothers, 14 were fathers, the average age of them is 35.34 years, and they all were the primary caregivers of the children. Education: junior high school and below were six (24.0%), high school were 12 (36.0%), college and above were 7 (40%). 25 parents were randomly assigned into two groups, 12 were in the observation group, and 13 were in the control group. The difference was not significant ($P > 0.05$) compared the proportion, age, education level and the children disease level of the two groups of parents.

1.2 Methods

1.2.1 Psychological status assess of the parents

Adapted Burke, Questionnaire (ABQ) questionnaire were used^[4]. The author modified some individual projects based on the specific situation of China, including eight kinds of emotional state, i.e., sadness, shock, anger, denial, pain, despair, fear and guilt. Take 0 = strongly to 3 = very strong, four evaluation scores ranged from 0 to 24 points, the higher score means higher sad degree. Reliability

Cronbach's alpha value is 0.935^[3].

1.2.2 Interventions

The control group received conventional treatment and care, and regular follow-up. The observation group received three months targeted family intervention according to the results of the assessment as follows:

1.2.2.1 Collective intervention ① HLD knowledge seminars by professionals for parents: twice a month, each time 60 ~ 90min, for three consecutive months, including the knowledge of HLD disease, medication knowledge, the importance and methods of diet care, the activities of daily living, and the role of harmonious family environment to control symptoms. After each lecture, we organized the parents to discuss and exchange the opinions and answer their questions. ② Setting up HLD hotline in the outpatient (opening every Saturday 8:30 to 11:30), neurology physicians of our hospital is responsible for answering and explaining, the parents of HLD children can ask their questions by telephone

- (1) **Psychological exchange** Family members with HLD children inevitably generate anxiety and fear. By the communication with them we found that the main reasons of anxiety and fear is the lack of understanding of the disease, the feeling of guilty for children and worried whether the brothers or sisters of HLD children is sick too when they know the HLD is a genetic disease. We explained the pathogenesis of the disease to family members of patients to inform them that the disease is curable genetic disease, and told them the treatment for the patient and the screening methods for other family members. This eased the anxiety of the families and gave them confidence to face the disease^[4].
- (2) **Treatment guiding** The families should develop a compliance behavior to the doctors, do not abuse their own drugs; do not change the dose and time. The drug should be stored in a cool, dry, dark, and fixed place. We explained the adverse reactions that may occur after taking the drug and told parents if the children feel sick they should come to hospital for medical treatment timely. The meals should for the HLD children should be light, easily digestible and rich in vitamins and fiber. The patients should maintain a low copper diet, do not drink the high-copper-containing water, do not eat high copper food such as seafood, nuts, mushrooms, beans and their products, do not use copper pots

when cooking. Adding trace elements such as zinc, iron and calcium is recommended because they are antagonist of copper and can promote copper excretion.

- (3) **Home care** Using a wet mopping for the floor, opening doors and windows regularly to ventilation. We suggested that the families purchase of air-cushion mattress, place intensity-regulate light fixture at bedside of the patients and the placed the patients in the low-rise building and low beds with shelf and air cushion mattress. We informed the potential security risks to the families to improve their security awareness, introduced the reasons early performance and dangers of pressure ulcers to the families. If the patient is bedridden, families should learn the expectoration method by chest percussion, which is an effective way to help the patients' sputum discharge.

1.2.2.2 Individual interventions Disease education and psychological counseling of the parents were specified to five specialist nurses for the specific circumstances of each family twice a month; each nurse was responsible for 3-4 families. Including: ① Adjustment of family communication, and learn to communicate with the children; to create a harmonious family environment, strengthen the exchange of feelings; to adjust expectations for children, such as the correct treatment of children with academic and daily living skills. ② The guidance for the parents of children to correctly identify adverse drug reactions, the recurrence symptoms and the corresponding approach, to improve the ability of parents to solve problems. ③ Answering the questions of parents of children patiently, to provide targeted guidance for children with behavioral skills and social function and rehabilitation. ④ Arrangement more than 2 times family gatherings during the intervention (including children), to encourage parents to discuss their care experience and the existing problems, to establish mutual support networks. Exchange contact means between nurses and patients to communicate at any time when problem happens.

1.2.3 Methods of evaluation After three months continuous intervention ABQ questionnaire is used to evaluate the intervention effects.

1.2.4 Statistical methods SPSS software was used for statistical analysis. Repeated measures analysis of variance was used.

2. Results

ABQ score before and after the intervention of the two groups of parents (Table 1)

Table 1. ABQ scores between two groups before and after intervention. $\bar{x} \pm s$

Group		Sadness	Shock	Anger	Denial	Pain	Despair	Fear	Guilt	Total
Control n=13	Before	2.79±1.2	2.08±1.2	2.11±0.9	2.66±1.6	2.98±1.4	2.24±1.6	2.13±1.3	2.34±1.4	2.32±1.2
	After	2.44±1.2	1.67±0.9	2.38±1.2	2.45±1.3	2.92±1.3	2.65±1.3	2.19±1.2	2.84±0.5	2.15±1.5
Observation n=12	Before	2.57±0.8	1.99±1.3	2.40±1.4	2.09±0.2	2.58±1.2	2.04±1.1	1.95±0.3	2.37±1.7	2.28±1.0
	After	1.64±1.1*	1.29±1.7	1.32±1.1*	1.15±1.4	1.77±0.9*	1.18±1.6	1.76±1.3	2.21±1.1	1.36±0.9*

Note: The two groups main effect, * P < 0.05.

The results showed that: the improvement was significantly better than the control in the observation group in the scores on sadness, anger, pain, and the total (P < 0.05).

3. Discussion

3.1 The reasons of family chronic sorrow

Chronic sorrow is a cycle, recurring pain or sorrow of parents or caregivers. It is also reported in the parents of children who suffered from mental retardation, developmental disabilities, early maturity, Down syndrome, neural tube defects, and chronic disease. Similarly, in the caregivers of adult patients with Parkinson's disease, multiple sclerosis, Alzheimer's disease and cancer it is also reported^[5]. In this study chronic sorrow may be related to the following factors: ① The HLD is a congenital genetic disease, parents tend to think that the pain of disease to the children is bought by themselves, so they feel pain, low self-esteem and guilt^[2]. ② Knowing little about the disease: multi-system damage caused HLD, the adverse effects of the drug, and psychiatric symptoms coupled with the worry about the physical and mental development of the children, after their studies and to join the army, employment, daily living, emotional issues all these things increase the chronic sorrow in the parents of HLD children^[6]. ③ Economic issue is also a reason of chronic sorrow. Long-term drug application, as well as to deal with the attendant adverse effects, and periodic review of the inspection fees: all these things above give the family enormous psychological pressure and economic pressure. ④ The children are very young, lack of self-expression and they can not take care of themselves, they need the care of family members for a long time. The parents have to spend much time to accompany their children so they do not have enough time with their jobs and learning. If this last for a long time, chronic sorrow happens. All these above give the parents of HLD children many psychological problems.

3.2 Reasonable intervention to alleviate the psychological pressure of the family members of HLD patients

Medical staff should give the parents of HLD children system and specification family support and health education, to help to improve the level of awareness of the disease and care of the children; should inform the parents the good prognosis of adherence treatment in this disease, so that they can see the

prospect of treatment, and establish the confidence to adhere treatment, and adhere to the standardized systematized treatment; should let children get a good therapeutic effect^[7], thus may improve the family atmosphere, to the ultimate improve the negative psychology of parents of children. Table1 showed that in sadness, anger, pain, as well as total scores the observed group of parents improved significantly better than the control group (P < 0.05), suggesting that a reasonable intervention can effectively alleviate the chronic sorrow in the family with HLD children.

The warmth and good care of the family has a large impact on the treatment and rehabilitation of the patient member. Family not only can protect and promote the function of members of the health, but also can provide all the necessary care and support to sick members. Therefore, being a nurse, we should give mental and psychological care and support to the family members of patients, and have conversation with them by charisma and good interpersonal skills, to establish a harmonious relationship of mutual trust, so that they are willing to accept the views of nurses, and consciously coordinate with the care and guidance.

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