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Original Article

Effects of multidisciplinary team continuous care model on psychological behavior and quality of life in children with β-thalassemia major

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Abstract: Objective: To explore the effects of a multidisciplinary team (MDT) continuous care model on psychological behavior and quality of life in children with β-thalassemia major (β-TM). Methods: A retrospective study was conducted on 90 children with β-TM who were hospitalized in the Department of Pediatrics, Affiliated Hospital of Youjiang Medical University for Nationalities from October 2021 to May 2022. According to nursing methods, the children were divided into a routine group and an experimental group, with 45 cases in each group. The routine group was intervened with routine nursing approaches, and the experimental group was intervened with the MDT continuous nursing mode on the basis of the control group. The psychological behavior [Positive and Negative Affect Scale for Children (PANAS-C)], quality of life (QoL) [Pediatric Quality of Life Inventory TM (PedsQLTM)] and satisfaction were compared between the two groups before and 6 months after intervention. The hemoglobin level and ferritin level of children after 3 months and 6 months of intervention were measured. The occurrence of complications and nursing satisfaction were recorded. The prognostic factors were further analyzed. Results: After the intervention, the positive emotion score, QoL score, hemoglobin level, satisfaction score in the experimental group were all higher than those in the conventional group, and the negative emotion score and ferritin level in the experimental group were all lower than those in the conventional group (all $P < 0.05$). The results of Cox analysis showed that the use of iron-removing drugs and arrhythmia/heart rate failure were risk factors affecting the prognosis of children with β-TM, while the MDT continuous nursing mode was a protective factor (all $P < 0.05$). Conclusion: The MDT continuous care model can effectively promote mental health in children with β-TM, improve their quality of life, medical satisfaction, ameliorate the degree of anemia in children, reduce the incidence of complications and improve the prognosis; thus, it is worthy of wide clinical application.

Keywords: Beta-thalassemia major, children, multidisciplinary, blood transfusion treatment, quality of life

Introduction

Beta-thalassemia major (β-TM) is one of the most common single-gene genetic diseases in the world [1]. It refers to a hereditary chronic hemolytic disease where the synthesis of β-globin peptide chain is decreased or completely stopped, resulting in a reduced amount of normal hemoglobin. Globally, 40,000 children with severe thalassemia are born every year [2], and it ranks first among birth defects in Guangxi [3]. The main complications of β-TM include anemia and iron overload, leading to functional damage of the heart and liver, as well as endocrine disorders leading to growth retardation, diabetes, etc. [4, 5]. Life-long blood transfusion and iron removal treatment are the main treatment methods for severe thalassemia; however, these methods are expensive, complicated, have a long cycle, and have many adverse reactions. Long-term treatment causes a heavy burden on patients, families,

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Table 1. Comparison of general data between the two groups

Item	Routine group (n=45)	Experimental group (n=45)	χ^2/t	P
Age (years, $\bar{x} \pm s$)	14 (11, 16.5)	15 (12.5, 16.5)	-0.785	0.432
Gender [n (%)]			0.711	0.399
Male	21 (46.67)	25 (55.56)		
Female	24 (53.33)	20 (44.44)		
Only child or not [n (%)]			0.182	0.670
Yes	20 (44.44)	18 (40.00)		
No	25 (55.56)	27 (60.00)		
Education level [n (%)]			0.185	0.667
Primary school and below	26 (57.78)	28 (62.22)		
Junior high school (including technical secondary school)	19 (42.22)	17 (37.78)		
Use of iron removal drugs [n (%)]			0.714	0.398
Yes	23 (51.11)	19 (42.22)		
No	22 (48.89)	26 (57.78)		
Regular blood transfusion			0.401	0.527
Yes	23 (51.11)	20 (44.44)		
No	22 (48.89)	25 (55.56)		

and the society [6]. At the same time, poor compliance increases adverse events related to iron loading, leading to increased morbidity, mortality, medical care utilization and nursing costs.

Routine nursing intervention pays more attention to the improvement of the patient's condition and the implementation of the treatment plan, but lacks refinement and systematization that cannot obtain the ideal intervention effect. Multidisciplinary team (MDT) care involves a relatively fixed working group formed by multiple professionals. For patients' diseases, specialists of different disciplines propose solutions that are beneficial to patients' diagnosis and treatment [7]. Many studies have confirmed that MDT is a better intervention for patients with chronic diseases [8, 9]. The research on the MDT continuous nursing model in China mainly focuses on hypertension, diabetes, coronary heart disease, etc. [10, 11], but it is relatively limited on the application in children with severe thalassemia. In view of this, we tried to investigate the application value of the MDT continuing care model in children with β-TM.

Materials and methods

Basic information

The clinical data of 90 children with β-TM hospitalized in the Department of Pediatrics of a Class III Grade A hospital in Baise, Guangxi from October 2021 to May 2022 were retrospectively analyzed in this study.

Inclusion criteria: ① Patients conforming to diagnostic criteria for β-TM [12]; ② Patients who received transfusion ≥ 8 times in our hospital in the past two years; ③ Patients aged 8-18 years old; ④ Patients who had received iron chelation therapy; ⑤ Patients with serum ferritin level (SF) higher than 1000 ng/ml.

Exclusion criteria: ① Patients with severe psychological problems; ② Patients with intellectual cognitive impairment; ③ Patients who were lost to follow-up.

The children were divided into a routine group and an experimental group according to the nursing mode, with 45 cases in each group. This study was approved by the Ethics Committee of Affiliated Hospital of Youjiang Medical University for Nationalities. The sex, age, whether they were an only child, education level and whether had used iron removing drugs between the two groups of children were comparable (all P > 0.05, **Table 1**).

Methods

Intervention methods of the routine group: The interventions in children of the routine group included blood transfusion, iron elimination, psychological care, and diet guidance, etc.

① At 9:00 every morning, the office nurse calls the Transfusion Unit for consultation; the types and quantities of blood products available for transfusion in children with β-TM are registered; ② The nurse asked the patients who needed to receive blood transfusion on the day of consultation and registered their information; ③ After admission, appropriate health education, psychological care and diet guidance were given; ④ The patients were given blood transfusion in strict accordance with the safe blood transfusion process; ⑤ The patients were informed of the time and precautions for next blood transfusion and taking iron removing drugs when leaving hospital; ⑥ Routine telephone follow-up was conducted after discharge.

Intervention methods of the experimental group: On the basis of the routine group, a MDT continuous nursing mode was adopted for experimental group. The specific methods are as follows.

(1) Construction of an MDT team. According to the disease characteristics and nursing needs of β-TM patients, a multidisciplinary nursing team with clear division of labor was constructed. ① Staff composition: 1 chief physician, 1 pediatric hematologist, 1 head nurse, 2 nurses in charge, 2 nurses (follow-up nurses), 1 pharmacist, and 1 social worker volunteer, all with bachelor's degree or above. ② Responsibilities of each member: the head nurse and the chief physician were responsible for the coordination among disciplines and team members, and arrange multidisciplinary collaborative consultation according to the needs of children; Pediatric hematologists were responsible for evaluating the condition of children, formulating treatment plans, and guiding professional knowledge. The follow-up nurse was responsible for establishing the children's files, understanding the health needs of each patient, and discussing with the team members to develop a health management plan and follow-up plan. The pharmacist was responsible for selecting appropriate iron removing drugs with the specialist according to the patient's condition and explaining in detail the precautions for taking the drugs and the symptoms and treatment methods of adverse reactions. The social worker volunteers were responsible for contacting the municipal Red Cross Society to find free blood donors and individuals or enterprises that can provide financial support for children.

(2) Determination and implementation of the intervention content. ① The specialist, pharmacist and nurse evaluated the patient's condition together, and the specialist formulated the treatment and nursing plan. ② Multidisciplinary collaboration meetings, including team members, children and their families, were held to determine the problems and needs of children. ③ Intervention plans were formulated according to problems and needs of patients, specifically including: class for parents of children from poor families was held once a month, focusing on disease management related knowledge; disease-related knowledge manuals were distributed; One-to-one consultation on family management knowledge; In addition to helping to find blood sources, social worker volunteers also helped to arrange college student volunteers to provide free guidance to children on their homework; and an online answering method of a WeChat group was established, and team members was arranged to answer questions online at a fixed time every month. ④ The intervention plan and measures were adjusted according to the effect of the intervention and the dynamic changes of the children. The evaluation was conducted at the 3rd and 6th month after intervention.

(3) Follow up. ① The care giver of the patients joined the health management WeChat group, which was uniformly managed by follow-up nurses, before patient discharge. Reminders and related precautions were automatically sent to patients at preset time nodes. The follow-up contents included the evaluation of blood transfusion efficacy, medication, adverse reactions after medication, and psychological status, etc. During the follow-up, the questions of patients were answered in time, and patients with anxiety and discomfort were given psychological counseling in time; Patients were instructed to take medicine on time at home, accurately record dosage, time, adverse reactions, etc., and ensure adequate rest and sleep. Patients were also educated on infection prevention. ② Telephone follow-up was conducted for those with problems in using smart phones according to the scheduled time nodes and inform the patients of the next follow-up plan.

After completion, the follow-up contents will be recorded in the patient's electronic file.

Evaluation index

Positive and negative affect scale for children (PANAS-C): The PANAS-C modified scale, compiled by Lanrent et al. [13], was used to evaluate the mental health of children. It includes two dimensions: positive emotion and negative emotion, each consisting of 10 domains. Each domain was scored by Linker 5, and the score was in direct proportion to the emotion intensity.

Pediatric quality of life inventory TM (PedsQL-TM): The PedsQLTM scale [14] was used to investigate the QoL of children. The scale includes 4 dimensions, including physiology, emotion, society and role function, with 23 items in total. The four dimensions contain 8, 5, 5, and 5 entries, respectively. The respondents answered according to the incidence of each item in the last month. The scores range from 0 to 4, representing five levels: never, almost never, sometimes, often, and always. Finally, they were converted into 100 points, 75 points, 50 points, 25 points, and 0 points. The final score of each dimension is the average score of all items in the dimension. The higher the score, the higher the quality of life.

Satisfaction survey: To investigate the satisfaction of children and their parents with the nursing work, the satisfaction questionnaire made by Affiliated Hospital of Youjiang Medical University for Nationalities was used. The questionnaire is categorized into 5 levels: "very satisfied", "quite satisfied", "fair", "quite dissatisfied" and "very dissatisfied". Among them, "very satisfied" and "quite satisfied" are combined into "satisfied", and the remaining three items are combined into "dissatisfied". The full scale of the questionnaire is 100 points, with 90 points or above indicating very satisfied, 75 to 89 points indicating quite satisfied, 55 to 74 points indicating fair, and 54 points or below indicating dissatisfaction. Total satisfaction = (number of very satisfied cases + number of quite satisfied cases)/total number of cases ×100.00%. Cronbach α coefficient of satisfaction questionnaire was 0.8.

Hemoglobin levels and ferritin levels: Venous blood was collected before intervention and 6 months after intervention, and hemoglobin and ferritin levels were measured to determine the degree of anemia and iron overload in the children.

Occurrence of complications: The complications of the two groups were recorded, including arrhythmia/heart rate failure, liver fibrosis, infection, and growth disorders.

Follow-up: Patients were followed up for 1 year (up to May 2023) in the form of outpatient or telephone follow-up, and the survival of patients were recorded.

Statistical methods

SPSS 25.0 software was used for data analysis. The measurement data conforming to normal distribution were represented by mean ± standard deviation and compared between groups using t-test; and those not conforming to normal distribution were represented by median and interquartile distance and compared between groups by using non-parametric test. The counting data were described by number (%) and analyzed using Chi-square test. Multivariate COX proportional risk model was used to screen the independent risk factors for patients' prognosis. The difference was statistically significant with $P < 0.05$.

Results

Comparison of psychological behavior between the two groups

Before the intervention, the positive emotion score and negative emotion score of PANAS-C scale in the experimental group were (36.49±4.35) points and (44.80±6.09) points, which were similar to (36.87±4.69) points and (43.96±6.09) points in routine group ($P > 0.05$). After the intervention, the positive emotion score of the experimental group was significantly higher than that of the routine group [(46.59±4.23) vs. (41.78±4.08) ($P < 0.05$)], while the negative emotion score in the experimental group was significantly lower than that of the routine group [(33.04±3.80) vs. (35.53±4.96) ($P < 0.05$)], as shown in **Figure 1**.

Comparison of quality of life between two groups

After 6 months of intervention, the total score of QoL in the routine group (54.27±9.19) was

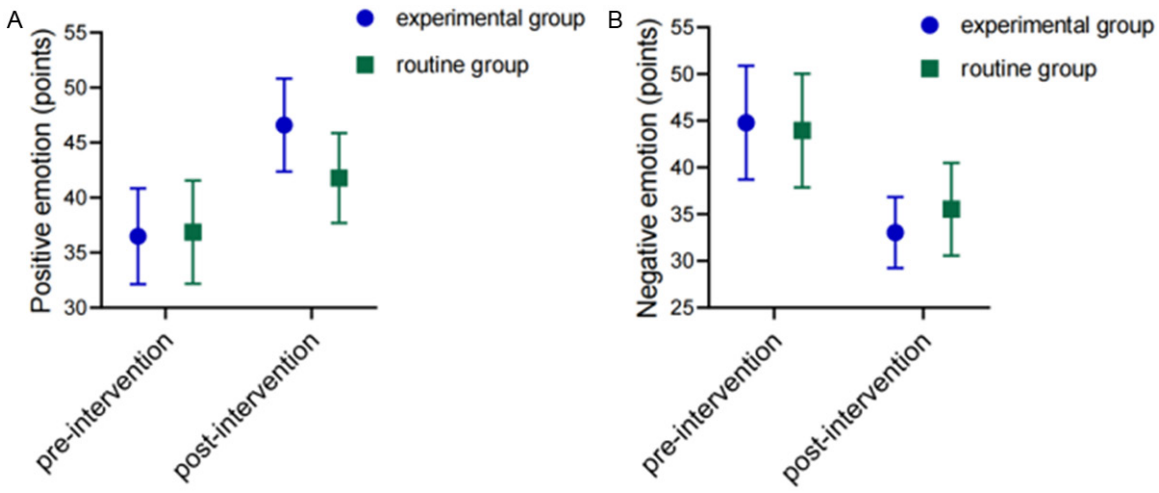

Figure 1. Comparison of PANAS-C scores between the two groups before and 6 months after intervention. A: Positive emotion score; B: Negative emotion score. PANAS-C: Positive and negative affect scale for children.

significantly lower than that in the experimental group (64.78±8.09) (P < 0.05), as shown in **Table 2**.

Comparison of nursing satisfaction between the two groups

Before the intervention, there were no statistical differences in nursing satisfaction between the two groups (both P > 0.05). After the intervention, the scores of satisfaction of experimental group were significantly higher than those of routine group (both P < 0.05), as shown in **Table 3**.

Comparison of complications between the two groups

The rates of arrhythmia/heart rate failure and infection in the experimental group were significantly lower than those in the routine group (all P < 0.05), as shown in **Table 4**.

Comparison of hemoglobin and ferritin between the two groups

Before the intervention, there were no significant differences in hemoglobin and ferritin between the two groups (both P > 0.05). After the intervention, the hemoglobin level of experimental group was significantly higher than that of conventional group, while the ferritin level was lower than that of conventional group (both P < 0.05), see **Table 5**.

Single factor analysis of factors affecting prognosis of children with β-TM

Patients were divided into a death group (n=16) and a survival group (n=74) according to their survival condition. There were significant differences in the use of iron removal drugs, arrhythmia/heart rate failure and nursing mode between the two groups (all P < 0.05), as shown in **Table 6**.

Multivariate analysis of factors influencing prognosis of children with β-TM

COX proportional risk model was used for multivariate analysis, and the assignment of study variables are shown in **Table 7**. The results showed that the use of iron removal drugs and arrhythmia/heart rate failure were the risk factors affecting the prognosis of children with β-TM, while the MDT continued care mode was the protective factor (all P < 0.05), see **Table 8**.

Discussion

Children born with β-thalassemia major (β-TM) occur in the highest incidence in western Guangxi [15, 16], making this area the forefront of prevention and control of severe thalassemia in China. For the children with β-TM, long course of disease, severe clinical manifestations, numerous complications, and lack of a specific cure bring heavy burden to the children and their families, which seriously threatens their

Table 2. Comparison of QoL scores of children in the two groups before and after intervention (χ±s)

Group	Physiological function		Emotional function		Social function		School performance		Total score	
	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention
Routine group (n=45)	18.84±5.24	18.53±4.35	13.17±2.29	12.64±2.51	12.84±2.09	12.87±2.48	10.47±2.44	10.22±2.95	55.33±7.22	54.27±9.19
Experimental group (n=45)	18.82±5.32	24.24±3.64	13.29±2.97	14.11±2.59	12.04±3.20	14.82±2.15	10.07±2.81	11.60±2.29	54.22±10.46	64.78±8.09
t	0.02	-6.76	-0.199	-2.727	1.41	-3.40	0.72	-2.47	0.59	-5.76
P	0.98	< 0.01	0.843	0.008	0.16	< 0.01	0.47	0.01	0.56	< 0.01

QoL: quality of life.

Table 3. Comparison of satisfaction between the two groups before and after intervention

Group	Nursing satisfaction	
	Pre-intervention	Post-intervention
Routine group (n=45)	4.02±2.09	3.96±2.10
Experimental group (n=45)	4.20±1.67	6.36±2.31
t	-0.445	-5.16
P	0.66	< 0.01

mental health and quality of life [17]. Some studies have pointed out that children with β-TM were prone to negative emotions, which affected their enthusiasm for treatment [19]. Psychological behavior refers to the activities of a person under the influence of various internal and external stimuli. Quality-of-life assessment comprehensively evaluates the physical function, psychological emotion and social adaptation, covering all aspects of the children's life [18]. The results of this study showed that after intervention, the negative emotion score of PANAS-C scale in the experimental group was significantly lower than that in the routine group, while the positive emotion score of PANAS-C scale and the quality of life score of patients in experimental group were much higher than those in the routine group. These results indicated that the MDT continued care model effectively promoted mental health and improved the quality of life of children with β-TM. In this study, MDT team members provided continuous care to patients with β-TM, which was beneficial to provide more professional and comprehensive continuous help to patients as early as possible when problems occurred, so as to reduce the patients' physical discomfort, promote their mental health and improve their quality of life.

Soliman and other scholars believe that the treatment compliance of children with thalassemia is closely related to their, as well as their families' awareness of β-thalassemia. Most children have insufficient knowledge of the disease and are prone to losing confidence in treatment in the long term [19]. Studies have pointed out that children with β-TM are prone to negative emotions due to long-term treatment, affecting the enthusiasm of children for treatment [20]. Previous studies have shown that good treatment compliance is the key to improve the survival rate and QoL of children [21, 22]. Al-Awamreh et al. reported that patients with thalassemia were satisfied with the quality of care and health services during hospitalization [23]. This study found that after intervention, the medication compliance score and satisfaction score of the experimental group were higher than those of the routine group, indicating that the MDT continuous nursing model can effectively improve the medical compliance and patients' satisfaction. MDT continuous nursing mode enables medical staff to explain the considerations in β-TM care to children and their families in a more targeted and systematic manner, which improves the medical compliance and nursing satisfaction of children. In addition, team members answer questions online and give one-on-one guidance. We-chat APP automatically sends reminders and related precautions to patients and their families at a pre-set time node, which can effectively improve nursing satisfaction.

It has been reported that the height and weight are related to the frequency of blood transfusion, the amount of hemoglobin and the iron removal treatment in children with thalassemia. The growth and development of children with regular blood transfusion and regular iron removal treatment are relatively good [24]. Children who receive regular blood transfusions must adhere to appropriate iron removal programs to prevent complications or death due to iron toxicity [25]. Studies have shown that serum ferritin can reflect the amount of stored iron and is essential for assessing the degree of iron deficiency in children [26]. This study found that after intervention, the hemoglobin level of the experimental group was significantly higher than that of conventional group, while the ferritin level was lower than that of conventional group (both $P < 0.05$). Also, the incidences of arrhythmia/heart rate failure and infection were lower than those in the routine group. These results suggest that MDT continuous nursing mode can effectively improve the hemoglobin level, reduce the ferritin level and reduce the occurrence of complications.

In this study, the factors affecting the prognosis of children with β-TM were further explored. It was found that the use of iron-removing drugs and arrhythmia/heart rate failure were risk fac-

Table 4. Comparison of complications between the two groups [n (%)]

Group	Arrhythmia/heart rate failure	Hepatic fibrosis	Infect	Growth disorders
Routine group (n=45)	10 (11.11)	6 (8.89)	9 (26.67)	6 (8.89)
Experimental group (n=45)	3 (4.44)	2 (4.44)	2 (11.11)	2 (4.44)
χ^2	4.046	1.359	5.075	1.359
P	0.036	0.244	0.024	0.244

Table 5. Comparison of hemoglobin and ferritin levels between the two groups before and 6 months after intervention

Group	Hemoglobin (g/L)		Serum ferritin (μg/L)	
	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention
Routine group (n=45)	74.04±13.49	93.42±6.38	4386.85 (3501.78, 5366.80)	7704.00 (5431.11, 10409.35)
Experimental group (n=45)	75.20±12.78	97.33±7.16	4260.33 (3188.68, 4861.50)	5724.22 (4963.50, 6750.58)
t	0.415	2.742	-0.945	-3.252
P	0.679	0.007	0.347	0.001

Table 6. Single factor analysis of the prognostic factors for children with β-TM

Factor	Death group (n=16)	Survival group (n=74)	χ^2/t	P
Age (years, $\bar{x}\pm s$)	9.56±1.97	8.99±1.72	1.182	0.240
Gender [n (%)]			0.422	0.516
Male	7 (43.75)	35 (47.30)		
Female	9 (56.25)	39 (52.70)		
Only child or not [n (%)]			3.280	0.070
Yes	10 (62.50)	28 (37.84)		
No	6 (37.50)	46 (62.16)		
Education level [n (%)]			2.141	0.143
Primary school and below	9 (56.25)	27 (36.49)		
Junior high school (including technical secondary school)	7 (43.75)	47 (63.51)		
Use of iron removal drugs [n (%)]			9.351	0.002
Yes	13 (81.25)	29 (39.19)		
No	3 (18.75)	45 (60.81)		
Regular blood transfusion			0.560	0.454
Yes	9 (56.25)	34 (45.95)		
No	7 (43.75)	40 (54.05)		
Arrhythmia/heart rate failure	7 (43.75)	68 (91.89)	13.523	< 0.001
Hepatic fibrosis	3 (18.75)	5 (6.76)	2.336	0.126
Infection	3 (18.75)	8 (10.53)	0.773	0.379
Growth disorders	1 (6.25)	7 (43.75)	0.167	0.683
Nursing model			4.865	0.027
Routine care	12 (75.00)	33 (44.59)		
MDT nursing model	4 (25.00)	41 (55.41)		

MDT: multidisciplinary team.

tors affecting the prognosis of children with β-TM, while the MDT continuous nursing model was a protective factor. Repeated blood transfusion therapy is the main cause of iron overload [27, 28]. Long-term iron removal and multiple blood transfusions can cause a slow accumulation of iron, and each input of red blood cells can increase iron in the body. Excessive

Table 7. Assignment

Variable	
Use iron-removing drugs	Yes =1, No =0
Arrhythmia/heart rate failure	Yes =1, No =0
Nursing model	Conventional care =1, MDT care mode =0

MDT: multidisciplinary team.

Table 8. Cox regression analysis of prognostic factors for children with β-TM

Item	B	SE	Wold	P	OR	95% CI
Use iron-removing drugs	2.126	0.661	10.342	0.001	8.384	2.294-30.639
Arrhythmia/heart rate failure	1.877	0.519	13.086	< 0.001	6.537	2.364-18.077
Nursing model	-1.282	0.587	4.767	0.029	0.277	0.088-0.877

iron is deposited in various organs, including the heart, liver, kidney, brain, and pancreas, causing organ failure [29]. A number of studies have confirmed that iron deposition in the myocardium leads to decreased left ventricular ejection fraction and heart failure. Heart disease is the main cause of death in patients with transfusion-dependent thalassemia [25, 30]. The MDT continuous nursing model can implement systematic and standardized all-round nursing for children, and significantly improve the treatment compliance of children with β-TM [31, 32]. At the same time, the MTD continuous nursing team members carry out health education after patient discharge, answer their questions, and explain the cause of their discomfort to them, so as to improve the prognosis and clinical efficacy of the patients.

The shortcoming of this study is that the intervention time was too short to show the advantages of the multidisciplinary collaboration model as β-TM is a chronic disease. It is hoped that in the future work, the service scope of multidisciplinary collaboration could be expanded that hospitals, communities and schools at all levels should be included, to establish a truly multi-disciplinary, multi-professional, multi-directional and multi-level chronic disease service system, further and comprehensively improving the quality of life of children with β-TM.

In summary, the MDT continuous care model can effectively promote mental health in children with β-TM, improve their quality of life and medical satisfaction, ameliorate the degree of anemia in children, reduce the incidence of complications, and improve their prognosis, thus, it is worthy of wide clinical practice.

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Disclosure of conflict of interest

None.

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