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***Retrospective Study***

**Application of narrative nursing in the families of children with biliary atresia: A retrospective study**

Zhang LH *et al*. Narrative nursing in children’s biliary atresia

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**Abstract**

BACKGROUND

Narrative nursing is an important clinical nursing intervention model. It is the practice of patient storytelling to share the essence of nursing. The current clinical intervention for biliary atresia (BA) mainly focuses on disease treatment and does not pay enough attention to the psychological state of family members.

AIM

To explore the application value of narrative nursing in the families of children with BA.

METHODS

Sixty-four family members of children with BA in our hospital from December 2017 to October 2020 were retrospectively included and were divided into a study group (*n* = 32) and a control group (*n* = 32). The control group was provided with routine nursing, while the study group was given narrative nursing on the basis of the control group. The scores of mood state (depression and anxiety), family members’ nursing ability, perceived stress, and nursing job satisfaction of the children’s families were calculated before and after the intervention.

RESULTS

Before intervention, there was no significant difference in the self-rating anxiety scale and self-rating depression scale scores between groups (*P* > 0.05). After intervention, the self-rating anxiety scale and self-rating depression scale scores in the study group were lower than those in the control group (both *P* = 0.000). Before intervention, the study group adjusted life to meet care needs, evaluated family members and social resources, dealt with personal emotions, responded to needs, and provided assistance, and the adaptive care role scores were not significantly different from those in the control group (*P* = 0.802, 0.819, 0.694, 0.796, and 0.686, respectively). After intervention, all scores were significantly lower in the study group than in the control group (all *P* < 0.0001). Before intervention, there was no significant difference in the child post-traumatic stress disorder symptom score (CPSS) score between groups (*P* = 0.615). After intervention, the CPSS scores were significantly lower than those before intervention in both groups and lower in the study group than in the control group (*P* < 0.0001). Nursing job satisfaction of the family members of the study group (93.75%) was higher than that of the control group (75.00%) (*P* = 0.039).

CONCLUSION

Narrative nursing with family members of children with BA can effectively alleviate negative emotions, reduce perceptual pressure, and improve nursing ability. Additionally, family members are more satisfied with nursing work.

**Key Words:** Narrative nursing; Biliary atresia; Negative emotions; Nursing ability; Retrospective study; Perceptual pressure

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**Core Tip:** This paper verified the positive effect of narrative nursing on children with congenital biliary atresia. The intervention of narrative nursing to the family members of children with biliary atresia can effectively alleviate their negative emotion, reduce the perceptual pressure, and improve their nursing ability.

**INTRODUCTION**

Biliary atresia (BA) is a common clinical disease with a high incidence in children. Moreover, in most children, BA is accompanied by jaundice, which is a great threat to the child’s physical and mental health and quality of life[1-5]. Surgery is an important measure for the clinical treatment of BA, in which hepatojejunostomy is most commonly used[6-8]. However, approximately 60% of children still require liver transplantation before the age of 20 years, and portal hypertension, nutritional dysplasia, and liver cirrhosis have a large impact on the long-term survival rate[9-12].

Most family members of children with BA experience serious anxiety and depression. In addition, serious cases can produce many extreme behaviors, such as abandoning of the child and causing secondary harm to the child. Meanwhile, the current clinical intervention for BA mainly focuses on disease treatment and does not pay enough attention to the psychological state of family members. This can lead to the failure of long-term standardized treatment and reexamination. In addition, it has a significant impact on the favorable outcomes of the disease. Consequently, the development of effective nursing interventions for the families of children with BA has become a research hotspot. Nursing interventions can not only regulate the physical and mental state of the child’s family members, it is also of great significance to ensure the improvement of the child’s disease.

As an important clinical nursing intervention model, nurses mainly use narrative nursing to help them reconstruct the meaning of life and disease stories by listening to and absorbing the stories of the intervention subjects. Moreover, it helps them to discover the main points of nursing during the intervention period to achieve the intervention effect[13,14].

Consequently, 64 family members of children with BA in our hospital were selected and divided into two groups (control group and study group) to explore the application value of narrative nursing.

**MATERIALS AND METHODS**

***General information***

A total of 64 family members of children with digital BA in our hospital from December 2017 to October 2020 were retrospectively included and were divided into two groups: Study group (*n* = 32) and control group (*n* = 32). In the study group, there were 17 male and 15 female participants, the age at admission ranged from 3 to 136 d, the average age was 82.97 ± 12.23 d, the range of body mass was 3.0 to 5.8 kg, and the average body mass was 4.40 ± 1.11 kg. Family members of the study group included 19 women and 13 men, aged 24–41 years with an average age of 32.56 ± 5.69 years. Their education level was junior middle school (*n* = 8), senior high school (*n* = 13), and junior college and above (*n* = 11). Regarding the education level, 8 of the family members were in junior middle school, 13 were in senior high school, and 11 were in junior college and above. The average monthly income of the family was < 3000 Yuan in 7 cases, 3000-5000 Yuan in 15 cases, and > 5000 Yuan in 10 cases.

In the control group, there were 19 male and 13 female patients; the age at admission ranged from 31 to 133 d; the average age was 81.91 ± 11.59 d, and their body mass was 3.2 to 5.7 kg (average body mass, 4.32 ± 1.07 kg). Family members of the control group included 21 women and 11 men with an average age of 33.21 ± 6.02 years. The education level was junior middle school (*n* = 6), senior high school (*n* = 16), and junior college and above (*n* = 10). The per capita monthly income of the family was < 3000 Yuan (*n* = 6), 3000-5000 Yuan (*n* = 17), and > 5000 Yuan (*n* = 9). Clinical data such as sex, age, body mass, education level, and per capita monthly income of the family were comparable between the two groups (*P* > 0.05).

***Selection criteria***

The inclusion criteria were as follows: (1) presence of lighter stool and yellow skin in the patient; (2) hepatomegaly was found on physical examination; (3) the family members of the children were educated till junior high school or above; (4) they were aware of this study and signed the consent form; and (5) the diagnosis was confirmed by magnetic resonance cholangiography, B-ultrasound, and intraoperative cholangiography. The exclusion criteria were as follows: (1) family members’ occupation in the medical field; (2) hearing impairment, cognitive impairment, speech communication disorder, and nervous system disease; and (3) children with immune system diseases or a blood coagulation disorder.

***Methods***

The control group underwent routine nursing, routine fasting, gastrointestinal decompression after surgery, and intravenous infusion of nutrient solutions for nutritional support. In addition, regular checks of the gastric tube, catheter, and subhepatic drainage tube were conducted to avoid compression or bending. The child’s head was raised approximately 45° off the bed after waking up, followed by close monitoring of the vital signs, surgical incision, and so forth. If there were conditions such as abdominal distension, abnormal heart rate, restlessness, and abnormal blood pressure fluctuation, the doctor was immediately informed and assisted with the corresponding measures.

The corresponding treatment is given according to the degree of pain in children. Relieving pain by playing soothing music, stroking children, and other measures for those with mild pain were used. If the pain was strong, administration of drug sedation and analgesia was performed, and the defecation frequency, character, and color were strictly observed. The family members of the patients were given a detailed explanation of the pathogenesis, treatment, and prognosis of BA through health education with the intention to alleviate the negative emotions caused by the disease.

Narrative nursing was adopted, and experienced nurses were selected to set up an intervention group based on the control group. First, training for the relevant contents of narrative nursing was performed, and nursing interventions were carried out after the training was complete.

**Preparation stage:** Nurses fully understood the basic information and condition of the children and actively communicated with the children’s families with an attitude of respect, humility, and empathy, with the intention to gain their trust and establish a harmonious nurse-patient relationship with the family members of the children.

**Enter the story of the child:** The nurse had a face-to-face conversation with the family without standard or frame, which was mainly based on receptive language and an open interview format, with questions such as “how do you understand the knowledge related to BA?”, “What was your initial understanding of BA?”, and “How is your sleep?” Nurses were instructed to smile and give an appropriate response to the family members’ complaints in the process of conversation, intending to guide the family members to talk fully about themselves to understand comprehensively the current serious problems, including the psychological problems, of the children’s families.

**Externalization and deconstruction of the problem:** The nurses were instructed to separate the problem from the family members of the children, help them to extract and name the problems that seriously trouble themselves, and strengthen the family members’ awareness that the problems had nothing to do with themselves. In addition, they discussed the family members’ control over the problem and their courage to deal with the problem so that the members could examine their stories more objectively. Second, we aimed to explore the impact of the problem on itself and others through deconstruction to ask the context of the analytical problem so as to increase its psychological space.

**Looking for exceptions:** The family members were guided to look for life outside the problem and to find the positive events that were ignored by them in the story. The positive force and positive identity implied are worthy of in-depth excavation. The goal was to let the family members of children think that they have the resources and abilities to solve the problem through this process.

**Reconstruct the story:** Transferring the positive power and identity hidden in the exceptional events to the practical problems that plague the patients and provide them with new choices to change the behavior and self-cognition of the children’s families in order to reconstruct the meaning of life. For example, the head nurse in the ward had a face-to-face conversation with a parent to help them name the problem that seriously besieged them as "unfair" in the process of the intervention as a mother who abandoned a child because of great life and ideological pressure. In addition, we demonstrated the impact of "unfairness" on the family members and others around them. Second, we looked for exceptional events, excavating the fragments neglected by the family members, and let them fully realize that they also have the resources and abilities to solve problems. Finally, the hidden positive forces were transferred to practical problems and alternative stories were developed: "despite great pressures in life, they could still continue to treat children through their own efforts and outside help, including the use of drip funding platforms, charitable funds, and so on. In addition, family members achieved psychological satisfaction, soul sublimation, and so on from the children’s attachment to the mother’s eye contact and body language. It was intended to improve the possibilities and opportunities to reconstruct a new life.

***Data evaluation***

The scores of mood state (depression and anxiety) of the two groups before and after the intervention were evaluated using the self-rating depression scale (SDS) and self-rating anxiety scale (SAS) scales: Mild depression: SDS score 53-62, moderate depression: 63-72, severe depression: ≥ 73; mild anxiety: SAS: 50-59, moderate anxiety: 60-69, severe anxiety: ≥ 69.

The scores of the care ability of family members of the two groups before and after the intervention were evaluated according to the caregiver care ability scale (FCTI), including adjusting life to meet care needs, evaluating family and social resources, dealing with personal emotions, responding to needs and providing assistance, and adapting to the role of care. Each dimension included five items, and each item was scored 0, 1, and 2 according to no difficulty, difficulty, and very difficult.

The perceived stress of the two groups before and after intervention was evaluated using the child post-traumatic stress disorder symptom score (CPSS), and the score of five grades was 43-56 for excessive pressure, 29-42 for obvious pressure, and 0-28 for mild stress.

Finally, the nursing job satisfaction of the family members of the two groups was assessed, and the nursing attitude and nursing quality were evaluated using a self-made nursing job satisfaction questionnaire, with a total of 10 points: Very satisfactory, ≥ 9 points; satisfaction, 7-8 points; dissatisfaction, ≤ 7 points. Nursing job satisfaction was very satisfactory rate + satisfaction rate.

***Statistical analysis***

The data were analyzed using SPSS22.0 (Armonk, NY, United States). Measurement data were described as mean ± SD and then analyzed with the Student’s *t*-test. The counting data were described as the frequency and constituent ratio (%) and then tested using the *χ*2 test. In addition, a non-parametric test was used to compare measurement data that did not meet the normal distribution. *P* < 0.05 indicated that the difference was statistically significant.

**RESULTS**

***Self-rating anxiety and depression scale scores***

There was no significant difference in the SAS and SDS scores between the study and control groups before the intervention (*P* = 0.662 and 0.757, respectively). The SAS and SDS scores in the study group were lower than those in the control group after the intervention (both *P* < 0.0001; Table 1).

***FCTI score***

The study group scores for adjusted life to meet care needs (4.15 ± 1.13), evaluated family members and social resources (3.99 ± 1.24), dealt with personal emotions (3.68 ± 0.99), responded to needs and provided assistance (3.77 ± 1.35), and adaptive care role (3.84 ± 1.26) were not significantly different from the control group score before the intervention (4.22 ± 1.09, *P* = 0.802; 4.06 ± 1.19, *P* = 0.819; 3.78 ± 1.03, *P* = 0.694; 3.86 ± 1.42, *P* = 0.796; and 3.97 ± 1.30, *P* = 0.686, respectively).

After the intervention, the abovementioned scores for the study group were significantly lower than those in the control group (2.00 ± 0.83 *vs* 3.08 ± 0.77, 1.65 ± 0.59 *vs* 2.44 ± 0.63, 1.13 ± 0.47 *vs* 2.05 ± 0.53, 1.79 ± 0.64 *vs* 2.82 ± 0.70, and 1.24 ± 0.62 *vs* 2.27 ± 0.66, respectively; all *P* < 0.0001; Table 2).

***CPSS score***

There was no significant difference in the CPSS scores between the study group and the control group before the intervention (*P* = 0. 615). However, after the intervention, the CPSS scores of the two groups were lower than those before the intervention (study group: 21.97 ± 2.51 *vs* 39.64 ± 4.46, *P* = 0.000; control group: 28.21 ± 3.35 *vs* 40.14 ± 3.39, *P* < 0.0001). In addition, after the intervention the study group score was significantly lower than that in the control group (*P* = 0.000; Table 3).

***Nursing job satisfaction of children’s family members***

The nursing job satisfaction of the family members of the study group (93.75%) was significantly higher than that of the control group (75.00%) (*P* = 0.039; Table 4).

**DISCUSSION**

The pathogenic factors of BA are complex and harmful; it not only causes great pain to the children themselves but also places heavy psychological and economic burdens on the children’s families, leading to negative coping strategies[15,16]. In addition, many clinical studies have examined safe and effective treatments for BA; however, most ignore the influence of the caregiver’s psychological state on the disease, which can result in poor communication and coordination, thus affecting the treatment and rehabilitation of the children. Consequently, there is an urgent need to find an intervention measure that can effectively improve the physical and mental state of children’s families.

Narrative nursing is a type of nursing intervention that uses narrative means to help the intervention subject abandon their previous life story and reconstruct a new story with a positive meaning[17,18]. The narrative nursing was defined as follows: Nurses listen to the disease stories of the intervention subjects through interviews, summarize and reflect on the stories, assist them in reconstructing the meaning of the disease or their life stories, and clarify the focus of nursing intervention to provide effective, scientific, and reasonable intervention programs for the intervention subjects. In addition, after the intervention of narrative nursing for the care families of critically ill intensive care unit patients, their degree of anxiety was effectively alleviated, and their satisfaction with nursing work was higher. In our study, the SDS, SAS, and CPSS scores in the study group were lower than those in the control group after using the intervention of narrative nursing for family members of children with BA in our hospital. This finding is consistent with the research results of the above scholars, indicating that narrative nursing can effectively relieve the negative emotions and perceptual pressure of the family members of children with BA.

The survival rate of high-risk BA infants is increasing with the rapid development of the social economy and the continuous improvement of medical care. However, the accompanying diseases also seriously perplex the families of children with BA. Among them, the psychological state of the family of child with BA is complicated, and there are negative emotions such as remorse, depression, despair, helplessness, and contradiction, which can take a toll both emotionally and economically. Medical staff have the responsibility to help the family members to understand correctly the disease and the treatment involved, to provide necessary psychological counseling and effective psychological interventions, to promote parents to cooperate with treatment, and to improve their mental health level. Narrative nursing can create a suitable platform for children’s families to vent their emotions, shorten the distance between nurses and patients, ensure that the stories of the children and their families are fully listened to, and effectively relieve bad emotions.

Additionally, the problems faced by family members are separated from the children and the parents themselves so that they can look at the problem objectively[19,20]. Therefore, narrative nursing can mobilize the potential and positive characteristics of children’s families by tapping into the flash events neglected by parents and the positive forces hidden behind them. This approach intends to make them strive to develop alternative stories and increase the possibility and opportunity to reconstruct a new life.

Moreover, the care ability of the main caregivers of family members is an important prerequisite and a basis for determining the quality of patient care. The stronger the ability of the main caregivers of the patients’ families, the easier it is to deal with the problems encountered during the care period. Finally, it improves the quality-of-care services for children.

Care ability involves many aspects that are difficult to quantify. Some studies refer to a self-designed scale, which lacks rationality and science. However, the FCTI effectively quantifies the caregiver’s care ability and evaluates family care ability systematically and comprehensively in five dimensions. The results showed that after the intervention, the scores of adjusting life to meet care needs, evaluating family and social resources, dealing with personal emotions, responding to needs and providing assistance, and adapting to the role of care in the study group were significantly lower in the study group than those in the control group. This result indicated that narrative nursing also has a significant advantage in improving the care ability of family members of children with BA, probably because the nursing program can effectively alleviate their negative emotions. Thus, family members are encouraged to actively face the disease and the treatment of their children, gradually accept the reality of the disease, and promote their own ability to take care of their children. In addition, the results showed that the nursing satisfaction of family members of the study group was higher than that of the control group. This result suggests that narrative nursing can also effectively deepen the recognition of nursing work for children with BA, help to reduce nurse-patient disputes, and establish a high-quality service image of the hospital.

**CONCLUSION**

Generally, narrative nursing interventions for family members of children with BA can effectively alleviate their negative emotions, reduce perceptual pressure, and improve their nursing ability. In addition, family members were more satisfied with the nursing work.

**ARTICLE HIGHLIGHTS**

***Research background***

At present, the clinical treatment of biliary atresia (BA) does not pay enough attention to the psychological state of family members.

***Research motivation***

This study ensures the psychological status of family members of children with BA during treatment.

***Research objectives***

This study aimed to explore the application value of narrative nursing in children with BA.

***Research methods***

Sixty-four family members of children with BA were included. The scores of mood state (depression and anxiety), family members’ nursing ability, perceived stress, and nursing job satisfaction of the children’s families were calculated before and after the intervention.

***Research results***

After the intervention, the child post-traumatic stress disorder symptom scores of the two groups were significantly lower than before the intervention, and the study group was lower than the control group; the nursing job satisfaction of family members in the study group was also significantly higher than that of the control group.

***Research conclusions***

Narrative nursing for the families of children with BA can effectively alleviate their negative emotions, reduce perceived pressure, improve nursing ability, and make family members more satisfied with nursing work.

***Research perspectives***

Narrative nursing will be more widely used in the treatment of children with BA.

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**Footnotes**

**Institutional review board statement:** This study was approved by the Huai’an Maternal and Child Hospital Ethics Committee (Approval No. 2020038).

**Informed consent statement:** Patients were not required to give informed consent to the study because the analysis used anonymous clinical data that were obtained after each patient agreed to treatment by written consent.

**Conflict-of-interest statement:** There is no conflict of interest.

**Data sharing statement:** No additional data are available.

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**Table 1 Comparison of self-rating anxiety and depression scale scores between the two groups (mean ± SD)**

|  |  |  |  |
| --- | --- | --- | --- |
| **Groups** | ***n*** | **SAS** | **SDS** |
| Before intervention |
| Study group  | 32 | 58.91 ± 5.04 | 60.79 ± 6.27 |
| Control group | 32 | 59.50 ± 5.68 | 61.28 ± 6.35 |
| *t* |  | 0.440 | 0.311 |
| *P* value |  | 0.662 | 0.757 |
| After intervention |
| study group  | 32 | 43.34 ± 4.60 | 45.65 ± 5.41 |
| control group | 32 | 50.59 ± 5.31 | 52.23 ± 5.69 |
| *t* |  | 5.838 | 4.741 |
| *P* value |  | 0.000a | 0.000a |

a*P* < 0.0001 between group *t*-test after intervention. SAS: Self-rating anxiety scale; SDS: Self-rating depression scale.

**Table 2 Comparison of caregiver care ability scale scores between the two groups (mean ± SD)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Groups** | ***n*** | **Adjust life to meet care needs** | **Assess family and social resources** | **Deal with personal emotions** | **Respond to needs and provide assistance** | **Adapt to the role of care** |
| Before intervention |
| Study group  | 32 | 4.15 ± 1.13 | 3.99 ± 1.24 | 3.68 ± 0.99 | 3.77 ± 1.35 | 3.84 ± 1.26 |
| Control group | 32 | 4.22 ± 1.09 | 4.06 ± 1.19 | 3.78 ± 1.03 | 3.86 ± 1.42 | 3.97 ± 1.30 |
| *t* |  | 0.252 | 0.230 | 0.396 | 0.260 | 0.406 |
| *P* value |  | 0.802 | 0.819 | 0.694 | 0.796 | 0.686 |
| After intervention |
| Study group  | 32 | 2.00 ± 0.83 | 1.65 ± 0.59 | 1.13 ± 0.47 | 1.79 ± 0.64 | 1.24 ± 0.62 |
| Control group | 32 | 3.08 ± 0.77 | 2.44 ± 0.63 | 2.05 ± 0.53 | 2.82 ± 0.70 | 2.27 ± 0.66 |
| *t* |  | 5.396 | 5.178 | 7.347 | 6.143 | 6.434 |
| *P* value |  | 0.000a | 0.000a | 0.000a | 0.000a | 0.000a |

a*P* < 0.0001 between group *t*-test after intervention.

**Table 3 Comparison of child post-traumatic stress disorder symptom scores between the two groups (mean ± SD)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Groups** | ***n*** | **Before intervention** | **After intervention** | ***t*** | ***P* value** |
| Study group  | 32 | 39.64 ± 4.46 | 21.97 ± 2.51 | 19.531 | 0.000a |
| Control group | 32 | 40.14 ± 3.39 | 28.21 ± 3.35 | 14.160 | 0.000a |
| *t* |  | 0.505 | 8.434 |  |  |
| *P* value |  | 0.615 | 0.000c |  |  |

a*P* = 0.000 *vs* before intervention.

c*P* = 0.000 between group *t*-test after intervention.

**Table 4 Comparison of nursing job satisfaction of family members of children in the two groups, *n* (%)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Groups** | ***n*** | **Very satisfied** | **Satisfied** | **Dissatisfied** | **Total satisfaction** |
| Study group  | 32 | 21 (65.63) | 9 (28.13) | 2 (6.25) | 30 (93.75) |
| Control group | 32 | 13 (40.63) | 11 (34.38) | 8 (25.00) | 24 (75.00) |
| *χ2* |  |  |  |  | 4.267 |
| *P* value |  |  |  |  | 0.039a |

a*P* < 0.05 *vs* control group.