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Observational Study

The psychological needs of parents of children with complicated congenital heart disease after admitting PICU: A questionnaire study

status and influencing factors of parents in children with CHD

Abstract

BACKGROUND

Parents of children with complicated congenital heart disease have different needs after surgery. Few literature reported the impact factors for psychological needs of patents of complicated congenital heart disease (CCHD).

AIM

To investigate the status quo of the needs of parents of children after surgery for complex congenital heart disease, and analyze the influencing factors, in order to provide a theoretical basis for formulating corresponding nursing countermeasures.

METHODS

A modified Chinese version of the Critical Care Family Needs Inventory (M-CCFNI) was used to select 200 parents of children with complex congenital heart disease after surgery within 72 h after admission to ICU in our hospital to conduct an online questionnaire survey. The aim was to understand the needs of parents in relation to the following five aspects: the support from medical staff, comfort of the parents themselves, the acquisition of information, their closeness to the children, and assurance of the child's condition.

RESULTS

Parents of children with complex congenital heart disease have a higher degree of demand, especially in terms of condition assurance, acquisition of information, and closeness to the children. The age, education level, and residence of the parents were related to the five dimensions of the needs of parents of children with complex congenital heart disease who have undergone surgery.

CONCLUSION

In practice, nurses should formulate corresponding nursing strategies based on the different cultural and social backgrounds of parents after complex congenital heart disease surgery to meet the different needs of children and their parents, and improve satisfaction. These findings provide a theoretical basis for constructing a family participatory nursing model for children in the intensive care unit in the future.

Key Words: congenital heart disease; family participation; psychological needs; nursing model

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Core Tip: In the treatment and nursing process of children with complicated congenital heart surgery, nursing staff should also pay attention to the mood changes of the caregiver, relieve and guide the bad mood, and help the caregiver establish a correct attitude and confidence in overcome the disease which can reduce the burden of caregivers through a variety of ways.

INTRODUCTION

According to relevant data (Liu *et al*,2015;Xie *et al*,2018;Zhao *et al*,2019), approximately 150 000-200 000 newborns in China suffer from congenital heart disease each year, accounting for about 0.8% of all live births. Congenital heart disease is the most common birth defect in China, and there are more and more complicated congenital heart diseases with any combination of "ventricular septal defect, atrial septal defect, patent ductus arteriosus, and simple pulmonary stenosis". Studies have shown that due to improvements in medical standards, surgical correction is the only way to cure complex congenital heart diseases. Due to the complexity of the operation, extracorporeal circulation and a long time period are required for anesthesia, postoperative close monitoring in the intensive care unit (ICU) and assisted supportive treatment of cardiopulmonary function to survive the most dangerous postoperative stage. The relatively closed ICU environment, long period of separation, lack of knowledge of the disease and other factors make the psychological pressure on parents far greater than on those with other diseases (Helm *et al*,2018;Kaugars *et al*,2018;Sood *et al*,2018). The unhealthy psychological problems of the parents of these children not only affect the rehabilitation of children, but can also cause conflict between the doctor and patient, and tension between the doctor and the parents (Bishop *et al*,2019). In this study, the parents of children with complicated congenital heart disease who underwent surgery were surveyed to understand their psychological needs, analyze influencing factors, identify major sources of stress, and explore intervention strategies to improve the medical care service model, improve nursing quality and satisfaction, and improve patient care.

MATERIALS AND METHODS

This study obtained authorization from Xia (Xia & Yan,2018), the original author of the modified Chinese version of the Parental Needs Inventory for Critically Ill Children (M-CCFNI) and consulted relevant national and international literature on the needs of parents of critically ill children. The current psychological needs of the parents of children with heart disease were evaluated. The basic information (general

demographic and social data) of the parents was designed by the researcher, and included the parents' gender, age, relationship to the child, cultural level, occupation, monthly family income, family residence and other related data. The M-CCFNI scale has 5 dimensions and a total of 37 items which include the support of medical staff (Support Scale, SS), parents' own comfort (Comfort Scale, CS), access to information (Information Scale, IS), and the need to be close to the children (Proximity Scale, PS), and the Assurance Scale (Assurance Scale, AS). The scale uses the Likert 4-point system for scoring. This study investigated the parents of children with congenital heart disease who had undergone surgery within 72 h after admission to the PICU.

This survey involved completing a questionnaire online. Firstly, the researcher adopted the domestic mature electronic questionnaire system design to form the electronic version of the questionnaire, and used repeated tests to ensure that the content of the electronic version of the questionnaire was completely consistent with the paper questionnaire. Then, the research team used the WeChat electronic version of the questionnaire to create a QR code for the questionnaire, and the survey participants used the mobile terminal to scan the code to complete the questionnaire. Each terminal was restricted to completing the questionnaire only once. This questionnaire survey adopted an anonymous method, and the parents were able to truly express their opinions without being affected by other factors. A dedicated person guided, explained, and confirmed the questionnaire recovery on the spot. As the questionnaire was completed online, missing data were avoided, and 200 valid questionnaires were obtained, with an effective recovery rate of 100%.

RESULTS

General information on parents of the children with complicated congenital heart disease is shown in Table 1.

DISCUSSION

The results of this study showed that the needs of parents of children with complex congenital heart disease after surgery are multifaceted, with a higher degree of demand as shown in Table 3-4, with an average of (3.62 ± 0.62) . In this study, single factor analysis of the needs of parents of children with congenital heart disease is shown in Table 5. It was found that age, educational level, and place of residence of the parents were correlated with the five dimensions of the needs of parents of these children. Therefore, more attention should be paid to the parents of children with complicated congenital heart disease who are admitted to the ICU and try to meet the needs of these parents.

This study showed that condition assurance is the most important requirement for parents of children with complicated congenital heart disease after surgery, which is consistent with the findings in other studies (Irons *et al*, 2018; Ruggiero *et al*, 2018). And three of the first five needs of parents are disease assurance needs. In this study, the score of "Hope that medical staff will do their best and be responsible" was the highest (3.82 ± 0.42) , and 83.3% of the parents thought this demand was very important. Within 72 h after admission to ICU, the patient's condition is still in an unstable state. Parents are most concerned about whether the child can be treated effectively to ensure that the child can pass through the critical period safely. It is suggested that medical staff should focus on meeting the disease guarantee needs of children's parents, including ensuring that children get the best treatment, and truthfully answer parents' questions, so that they can tell them about the progress of the disease. In the actual clinical work, when the child is sick, the family can only rely on the treatment and care of the medical staff, and often have high expectations for the treatment and prognosis of the child. When the treatment outcome of the child is not satisfactory, it is difficult for the family to understand and accept it. It is very easy to produce doctor-patient conflicts. Therefore, ICU medical staff should not only make the family members of patients feel the hope of improvement of the patient's condition, but also let the family members correctly understand the prognosis of the patients, and form a correct and reasonable

psychological expectation of the prognosis of the patients, so as to reduce the conflict between doctors and patients.

In addition, the demand for information was also relatively high. Nurses must provide parents with information about the child, such as the child's recovery from the disease, medication use, and mental state while the child's condition is stable. In this study, the need to get close to the child was slightly lower than the need to obtain information. In a study of the needs of parents in the ICU of newborns by Thomi *et al*, "being with the child" was the most important need (Thomi *et al*, 2019). The children and their parents are prone to developing unhealthy emotions such as separation anxiety, which is not conducive to the children's early rehabilitation and nurse-patient communication. Therefore, when the child or the parent has special circumstances, the nursing staff should adjust the visiting time and frequency in a timely manner. It is also important to keep in touch with the parents of the child in a variety of ways, so that they can understand the changes in the child's condition dynamically and in real time, meet the psychological needs for the child's closeness, and relieve nervousness. At the same time, the establishment of a semi-closed or fully open PICU management model or family participatory nursing model can be explored.

This study found that parents of children with complex congenital disease place too much emphasis on the treatment of children, and they neglect to pay attention to themselves. Gramszlo *et al* (Gramszlo *et al*, 2019) believe that the concept of centering on the parents should be integrated into the ICU's child-centered medical care service model. In 2019, Golfenshtein N *et al* (Golfenshtein *et al*, 2019) showed that if the needs of parents of ICU children can be effectively met, this can reduce their anxiety, provide a good social support system for children, and promote their recovery. This also suggests that nursing staff should pay attention to providing psychological support services to parents of children during the nursing process.

CONCLUSION

With the continuous renewal of nursing concepts, the importance of child- and parent-centered concepts and family support therapy in the treatment process has been increasingly recognized by hospital administrators and clinical nursing staff. In the treatment and nursing process of children who undergo complicated surgery for congenital heart disease, nursing staff should also pay attention to the mood changes of the caregiver, relieve and guide their emotions, and help the caregiver establish the correct attitude and confidence to overcome the disease which can reduce the burden of caregivers in a variety of ways (McClung *et al*,2018), in order to provide more and better positive support to children and promote their recovery. On the other hand, satisfying the reasonable psychological needs of the parents of these children can improve satisfaction and help build a harmonious nurse-patient relationship.

ARTICLE HIGHLIGHTS

Research background

Parents of children with complicated congenital heart disease have different needs after surgery. Few literature reported the impact factors for psychological needs of patents of complicated congenital heart disease (CCHD).

Research motivation

To investigate the status quo of the needs of parents of children after surgery for complex congenital heart disease, and analyze the influencing factors, in order to provide a theoretical basis for formulating corresponding nursing countermeasures.

Research objectives

In order to provide a theoretical basis for formulating corresponding nursing countermeasures.

Research methods

A modified Chinese version of the Critical Care Family Needs Inventory (M-CCFNI) was used to select 200 parents of children with complex congenital heart disease after surgery within 72 h after admission to ICU in our hospital to conduct an online questionnaire survey. The aim was to understand the needs of parents in relation to the following five aspects: the support from medical staff, comfort of the parents themselves, the acquisition of information, their closeness to the children, and assurance of the child's condition.

Research results

Parents of children with complex congenital heart disease have a higher degree of demand, especially in terms of condition assurance, acquisition of information, and closeness to the children. The age, education level, and residence of the parents were related to the five dimensions of the needs of parents of children with complex congenital heart disease who have undergone surgery.

Research conclusions

In practice, nurses should formulate corresponding nursing strategies based on the different cultural and social backgrounds of parents after complex congenital heart disease surgery to meet the different needs of children and their parents, and improve satisfaction. These findings provide a theoretical basis for constructing a family participatory nursing model for children in the intensive care unit in the future.

Research perspectives

How to provide psychological intervention for parents of children admitted to ICU after complex congenital heart disease.

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