The Psychological Experiences and Demands of Mothers of Ambulatory Surgery Children with Congenital Cataract: A Qualitative Study

Wanxia Zhang & Zhangfang Ma

Abstract

Objective: To explore the psychological experiences and demands of mothers of ambulatory surgery children with congenital cataract before and after ambulatory surgery in a cohort of Chinese patients.
Methods: All twenty mothers of ambulatory surgery children with congenital cataract at a large tertiary hospital were recruited for a semi-structured interview face-to-face. The phenomenological methodology was used. The data had been analyzed by Colaizzi's method.

- **Results:** Analysis showed five themes. They were anxiety and worry, the impacts on family and social relations, urgent demands for the knowledge about the general anesthesia, eager to talk and be heard, and urgent demands for family care skills.
- **Conclusion:** The Nurses should understand the psychological experiences and demands of mothers of ambulatory surgery children with congenital cataract, provide emotional support where required and help mothers to build positive coping style so as to promote their physical and mental health.

Keywords: Care Experience, Congenital Cataract, Qualitative Research, Mother, Ambulatory Surgery. Authors' Address: Department of Ophthalmology, Beijing Tongren Hospital, Capital Medical University, China. Corresponding Author: Zhangfang Ma, 1969-, Nurse-in-Charge, Beijing Tongren Hospital, Beijing, China. *Email*:<u>mazf1602@126.com</u>

Introduction

Congenital cataract is the leading cause of blindness in children worldwide. It has serious influences on children's visual development and visual acuity. Surgery is still the main method in treatment [1]. Ambulatory surgery under general anesthesia can reduce the waiting time for children with congenital cataract. But their parents have many serious psychological problems. What concerns them is that their children need to have surgery under general anesthesia and be hospitalized for less than 1 day. Mothers of children are the primary caregivers and need more attention. The purpose of the present study was to understand the psychological experiences and demands of mothers of ambulatory surgery children with congenital cataract by Colaizzi's method, and to provide the basis for the development of scientific and effective interventions.

Materials and Methods

Materials

A convenience sampling method was used to recruit the mothers of ambulatory surgery children with congenital cataract in ophthalmic day-case unit of our hospital from March to August 2016. The sample size is determined by the principle of data saturation. When the content is no longer new, the data is saturated [2]. The inclusion criteria of the present study: 1) The mothers of ambulatory surgery children with congenital cataract; 2) Having a certain ability of language expression, clear consciousness and clear thinking, 3) No history of mental illness and agreed to be interviewed. When we visited to the twentieth mother, the information achieved saturation.

In 20 cases of mothers, their age was between 24 and 42 years old. The educational background of 12 mothers was high school and above, and the educational background of 8 mothers was junior middle school. The occupation of 8 cases was farmer. The occupation of 6 cases was clerk. The occupation of 1 case was teacher. The occupation of 5 cases was other. The children's age was between 2 and 5 years old. 11 children were male. 9 children were female. The complications of 2 children were congenital iris deficiency and nystagmus. The complication of 15 children was amblyopia. The complications of 2 children were strabismus and nystagmus. The complication of 1 child was strabismus.

Methods

Guided by phenomenological method in qualitative research, we used a semi-structured interview. We followed the ethical principles and signed the informed consents wih these 20 mothers. We respected the willingness of the research subjects and made a commitment that the research materials are strictly confidential [3]. Questions for semistructured interview: 1) How do you feel about caring your child before and after the surgery? 2) What difficulties do you have before and after surgery? How do you cope with the difficulties? 3) What do you need most now? In what way would you like to get assistance?

The same researcher was responsible for all the interviews. The time of the interview was 1 day after discharge. Each interview lasted from 30 to 40 minutes. The respondents were numbered in sequence from C1 to C20. The information was collected by means of recording and transcripts on the spot. The recordings were converted into text after the interviews. The data was analyzed by Colaizzi's method [4]. The research themes were generalized in detail below.

Results

Anxiety and Worry

When the children were diagnosed with congenital cataract, all the mothers showed shock at first, and then guilt, remorse and helplessness. They all expressed uncertainty and worry. The mothers' anxiety were also more serious after ambulatory surgery. They worried about the effectiveness of surgery and general anesthesia, but also worried about their poor care skill. C1: At first, I'm shocked. It's eye disease. How does my child live later? C6: My child is still so small. It is my fault. I did not give birth to him very well. C13: My child would have surgery today, and discharge tomorrow. I feel insecure. C9: I often worry about the failure of the operation. C5: Will the cry affect the effect of the surgery? C10: My child had been crying after surgery. She pulled the gauze. Is the surgery failed? C2: Is the child's cry and scream because of insufficient anesthetic's dosage?

The impacts on family and social relations

The mothers expressed that the family relations of these mothers were influenced. Some family members considered mothers were the source of the heredity and blamed them. Because the child fell sick, the mothers had been forced to stop working. Their social circle was diminished due to working stopped and changed social role. C3:My mother-in-law thought that this disease was inherited from me, as soon as she knew the name of congenital cataract. It's unreasonable. C17: The quarrel between my parents and my husband's parents has been going on, since my child fell ill. They blame each other. My husband doesn't say a word. C16: When others ask about the reason of the child's illness, I am very sick and tired. C12: I have not been at work, since my child fell ill. I heard that the child could have amblyopia training after surgery. I hope some social groups or associations can help me and my child. C2: I hope the hospital can held more knowledge lectures and provide us the way of obtaining the relevant knowledge.

Urgent demands for the knowledge about the general anesthesia

The mothers all expressed their demands for the knowledge about the process and adverse reaction of general anesthesia. C19: General anesthesia is a blind spot for me. How to acquire this knowledge? C14: Will general anesthesia not affect the child's intellectual development? No harm to the body? C7: How to have the general anesthesia? Is it an injection or intubation?

Eager to talk and be heard

The mothers of this group all expressed their desire to talk and be heard. They hoped to be heard by the doctors and nurses. They hoped to gain the psychological support of other mothers of the children with the common disease. C18: Sometime I feel depressed in the face of my child and family. Do something else and find someone to chat, and then I feel a little better. C8: I have a lot of questions to ask the doctor, but the doctor is too busy to have time. C20: If the doctor can explain in more detail, I will feel better mentally. C11: It's better to chat about these annoying things with outsiders than with my family. Our several mothers have built a WeChat group. We feel very well.

Urgent demands for family care skills

The mothers all expressed concerns about the time of hospitalization. They mentally depended on the nurse's care and guidance. Because of the lack of the family care skills and relevant knowledge, they had less confidence to take care of their children at home after ambulatory surgery. C4: I'm afraid I can't care my child very well, because the hospital stay is so short. C15: the nurse has told me how to take care of my child after surgery, but what if I forget?

Discussion

Pay attention to the psychological status of the mothers and put emphasis on listen.

All the mothers in this group showed anxiety and worry. This is consistent with other studies in China [5]. Ambulatory surgery can

reduce the waiting time and hospitalization time for children with congenital cataract, but at the same time the mothers became more worried about the risk of the hospitalization for less than one day. The caregivers with high burden experience tend to pay less attention to their health [6]. Thus the nurses should pay attention to the psychological status of the mothers of the children with congenital cataract before and after ambulatory surgery. The nurses need to understand psychological experiences and demands of the mothers, and then in hospital the nurses provide psychological nursing care to them at the right moment. In addition, the nurses should ask carefully, tell patiently and remind clearly the important things during the preoperative telephone interview and the postoperative telephone follow-up. The nurses could analyze the existing psychological problems of mothers, help them to face their problems squarely and provide them the timely psychological counseling. Meanwhile, the "listen" training of nurses must be strengthened. Though this training, the nurses might master the "listen" skills so as to provide better psychological care for mothers of children with congenital cataract.

Strengthen the health education of the knowledge of general anesthesia and family care skills and reduce the mothers' uncertainty and concerns about the family care risk of ambulatory surgery.

The sense of uncertainty has become an important and common problem in the process of making medical decision and caring for patients [7]. The symptoms and signs of congenital cataract make a psychological impact on the mothers of the children with congenital cataract. They felt an overwhelming sense of uncertainty about this disease. The uncertainty sense of diseases is positively correlated with the lack of information [8]. Because of the hospitalization for less than 1 day, the timing and time of health education is not enough relatively in hospital. Thus the health education of the knowledge of general anesthesia and family care skills is not enough for the mothers. This health education need be strengthened in ophthalmological ambulatory surgery center. Meanwhile, the psychological nursing is provided in the process of health education. Through telephone interview, nurses can provide timely psychological counseling for mothers of children and strengthen the knowledge introduction of general anesthesia before surgery so as to reduce the fear of general anesthesia. Through strengthening the guidance of family care skills and the inform of the continuous nursing, fundamentally build their confidence in family care. It would help to relieve their concern about the risk of the hospitalization for less than 1 day and reduce all kinds of uncertainty sense. Finally it would help to reduce their psychological burdens.

Building family and social psychological support system

When the individual lacks the support system, he will have a strong sense of social isolation, and be unable to cope with various problems in life [9]. Family is a very important social support system [10]. A good family-social psychological support system can alleviate or relieve the psychological problems of caregivers. The nursing staff needs to master the relevant psychological knowledge so as to be able to help to build a stable family- social psychological support system. Strengthen health education about the etiology of congenital cataract and psychological knowledge for the children's family members. It would help them to correctly treat the disease itself, relieve the negative emotions and actively cope with the problem. The mothers stopped working and contacted with the parents of children with the same disease every day. It is easy to increase their anxiety. In the present study, 16 mothers started work again after leaving the child for a short time. They felt that the negative emotions were relieved. Thus we should suggest that the members of family may take care of the children in turn and duly rest and separate oneself from the

negative emotion environment. Nurses should help the mothers to use the positive coping style such as solving the problems and seeking help.

Summary

In summary, the nurses should understand the psychological experiences and demands of mothers of children with congenital cataract before and after ambulatory surgery. Positive coping style and emotional support should be offered for these mothers. It would help to promote the physical and mental health of these mothers.

Funding source

There was no external funding or sponsorship associated with this project.

Conflict of interest

There was no conflict of interest from the authors related to this paper.

The present study had been approved by the ethics committee of Beijing Tongren Hospital

References

- Zhou Zhou, Li Li. Surgical treatment and progress of congenital cataract. *International Journal of Ophthalmology* 2014; (11):1978-81.
- Papastavrou E, Charalambous A, Tsangari H. How do informal caregivers with cancer cope: A descriptive study of the coping strategies employed. *European Journal of Oncology Nursing* 2012;16(3):258-263.
- Chi Zhang, Junqiao Wang, Yan Hu. Caring experience of family caregivers of elderly hospice patients at home: a qualitative study. *Journal of Nursing Science* 2011;26(19): 75-78.
- 4. Ming Liu. **Qualitative research of nursing.** Beijing: People's Medical Publishing House, 2008:53-60.
- Wanxia Zhang, Xinbei Zhang. Investigation on the status quo of psychological health of parents of children with congenital cataract and nursing intervention. *Chinese Nursing Research* 2010; 24(6):1545-6.
- Chen ML, Hu LC. The generalizability of caregiver strain index in family caregivers of cancer patients. *International Journal of Nursing Studies* 2002;**39(8)**:823-9.
- Han PKJ, Klein WMP, Arora NK. Varieties of uncertainty in health care: A conceptual taxonomy. Medical Decision Making 2011;31(6):828-38.
- Xiaoling Sun. Research progress of the uncertainty sense of hospitalized patients. *Journal of Nursing Science* 2009; 24(2):89-91.
- Lohne V, Miaskowski C, Rustoen T. The relationship between hope and caregiver strain in family caregivers of patients with advanced cancer. *Cancer Nursing* 2012;35(2):99-105.
- Chow W, Boman KK. Parents perceptions of support when a child has cancer. A longitudinal perspective. *Journal of Cancer Nursing* 2007;**30(4)**:294-301.