Problems in Children with Ventricular Septal Defect (VSD) Prior to Surgery in Rural Thailand

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Abstract — Children with VSD in rural Thailand experienced long waiting times for surgery. To understand the caregivers’ problems in their cultural context, an ethnographic approach was used to explore and understand them, especially the experiences of how the caregivers managed the care of their child with VSD prior to surgery. The ten main caregivers of children with VSD and ten health professionals who dealt with these children had been purposively selected. Data were collected through in-depth interviews, field notes, observations, and photographs with the ten main caregivers at their homes and the health professionals interviewed at the hospital. A thematic approach was used to analyse the data. The triangulated findings generated themes indicating that the problems these children and their caregivers encountered were: 1) insufficient information and supporting advice; 2) difficulty in gaining or maintaining the child’s weight; 3) financial issues for attending the specialist hospital and 4) respiratory infection complications.

The findings suggested that, particularly in rural Thailand, there is a need to provide sufficient information from specialist health professionals, as well as adequate useful resources at the clinic and continuous monitoring of caregivers’ knowledge need to be improved to enhance the ability of caregivers in caring for children with VSD.

Keywords — ventricular septal defect, prior to surgery, ethnography, rural Thailand, caregivers.

I. INTRODUCTION

Ventricular septal defect (VSD) is one of the most common congenital heart diseases (CHD), accounting for up to 40% of all cardiac anomalies. The incidence of congenital heart disease was 8 to 10 infants for every 1,000 live births as a report focusing only on the incidence of VSD in Thailand has yet to be compiled. The situation is that Thai children who need cardiac surgery are often put on a waiting list and followed-up in order of severity. As a result of further delays for undergoing surgery, this places children with CHD at greater risk from recurrent complications. In this situation it might be because an isolated VSD is not regarded as a critical cardiac problem when compared with the others on the list who have more complex or urgent conditions. Children with VSD rely on parents and/or other family members to look after them and provide care at home while they wait for surgery or the spontaneous closure of the VSD defect. Thai families tend to have close relationships within the family group and help each other from one generation to the next. In taking care of these children, caregivers need to assess and monitor signs and symptoms, growth and development, and any complications that may occur. Whilst the child waits for a better prognosis or surgery, they will be brought up at home with occasional visits to the pediatric cardiologist under the schedule of follow-up appointments.

Previous studies also showed that there was a gap in information in this area. There have been no prior studies, in either English or Thai publications, which explore the best way to support caregivers in helping their children. None of the studies focused on VSD in terms of maintaining their health prior to surgery and none of them considered the specific issues that might occur in rural Thailand. This study will help to understand their problems prior to surgery to help prepare them physically.

II. METHODOLOGY

An ethnographic approach was used to explore and understand the caregivers’ problems in their cultural context. Purposive sampling was used to recruit ten main caregivers who were taking care of children with VSD who were waiting for surgery, and ten health professionals who dealt with these children, to ascertain any differences in perspective between the professionals and the caregivers. Data were collected through in-depth interviews, field notes, observations, and photographs with the ten main
caregivers at their homes and the health professionals interviewed at a regional hospital. A thematic approach was used to analyze the data.

III. RESULT AND DISCUSSION

The triangulated findings generated themes indicating that the problems these children and their caregivers encountered were:

1) Insufficient information and supporting advice;
   The information showed that the workload of the doctors and nurses was extremely high because of the lack of a support team. This made it more difficult for health personnel to provide advice in individual cases. Also the information provided at the clinic was just general advice about caring not practical advice for taking care of children with VSD, especially for the elder caregivers and/or the caregiver in the rural area. Interestingly, this study identified that the main caregiver was not always the person who took the child to hospital and received the advice directly from the doctor, and did not have effective transfer information from the one who met the doctor at the clinic and the main caregiver who were mainly the grandmother. However, they learnt that the caregivers needed advice. It was not only a lack of time and resource, but also the support team, who had the specific knowledge to advise the caregivers of children with VSD.

2) Difficulty in gaining or maintaining the child’s weight;
   The analyzed data demonstrated that a common problem of children with VSD in Thailand identified by the pediatricians, the pediatric nurses and the caregivers, was that the children with VSD had difficulty in gaining weight which was related to many factors including the severity of pathology and nutritional management. Most of the caregivers were still worried about symptoms and whether the child would grow then tried to feed their child. They were also thinking positively, that even though their child was quite small, the child could still grow; however, some caregivers had also concerns about the development of their children’s intelligence.

3) Financial issues for attending the specialist hospital sometimes resulting in missed follow-up appointments;
   People in rural areas were not economically rich but they could have a reasonable quality of life in their context. However, if they had a sick child who needed treatment, it impacted on the whole family’s economic status. In cases where they needed to take the child to a specialist hospital some distance away from where they lived, they would be obliged to stop working. This could affect their regular income and in some instances the husband needed to obtain better paid work, to balance the budget, which was usually a long distance from the family home. Some families mentioned that they sometimes missed follow-up appointments at the specialist hospital in Bangkok when they were really struggling for money. However, all participants confirmed that they did the best they could in taking care of the child.

4) Respiratory infection complications.
   According to the caregiver interviews, children with VSD were brought up in different circumstances, based on their caregiver’s knowledge and ability, and the family’s financial status. These children needed a monitoring care, medical treatment and protection from complications. Respiratory infection was the most concern and reported from the caregivers as they mentioned that it can be one of the factors that would impact to the child’s growth, especially when the child was still young. The caregivers also reported that their child could easier get a cold than a healthy child.

IV. CONCLUSIONS

The findings indicated that these children and their caregivers encountered insufficient information and supporting advice provided at the regional hospital, financial issues when attending the specialist hospital and difficulty in gaining or maintaining the child’s weight which impacted from their nutritional management and complications. Having undertaken this study and experienced the data collection I can confirm that using an ethnographic approach allowed me to access detailed, in-depth, rich data from both the caregivers and health professional.
V. FURTHER RESEARCH

Any further research should be concerned with developing a large scale ethnographic approach and should take place in other areas, not only rural but also urban, to see whether they have similar or different problems. If the findings are the same as this current study, then this can be used for creating a standard of care for children with VSD. However, if they have different problems, then the information needs to be specifically categorised for rural areas and urban areas.

VI. ACKNOWLEDGEMENT

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VII. REFERENCES