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## Original Article

# Discharge planning for children with ventricular septal defect and pulmonary arterial hypertension in China

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## ABSTRACT

**Objective:** To evaluate the effectiveness of discharge planning on maternal caring knowledge, maternal caring behavior, maternal discharge readiness and the rehospitalization of children with ventricular septal defect and pulmonary arterial hypertension (VSD-PAH).

**Background:** Children with congenital heart disease (CHD) with pulmonary arterial hypertension (PAH) have more complications after surgery than those without PAH. Discharge planning is an effective strategy to help children leave the hospital safely, and receive appropriate care after discharge.

**Methods:** A quasi-experimental design was used. Sixty children and their mothers were recruited and divided into two groups: the control group received conventional care, the intervention group received both conventional care and additional discharge planning care.

**Results:** (1) After admission, maternal caring knowledge between the two groups was similar. (2) At discharge, maternal discharge readiness, maternal caring knowledge and maternal caring behavior in the intervention group was significantly higher compared to the control group ( $t = 3.35, p = 0.001$ ;  $F = 84.74, p < 0.001$ ;  $F = 23.82, p < 0.001$ ). This difference persisted after discharge, and was evident at one month and three months after discharge. (3) However, no significant difference in the readmission rate of children after discharge was evident between the two groups.

**Conclusions:** Discharge planning improves the maternal discharge readiness, maternal caring knowledge and maternal caring behaviors. However, this planning did not reduce the readmission rate of children with CHD-PAH.

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## 1. Introduction

In China, about 15,000 babies are born with congenital heart disease every year [1]. Significant advances in the field of pediatric cardiology and cardiac surgery, together with improvements in other advanced technologies, such as extracorporeal membrane oxygenation (ECMO) and heart transplantation, have resulted in a growing population of children living with congenital heart disease (CHD) [2]. However, CHD with pulmonary arterial hypertension (PAH) is still a challenge for medical professionals. PAH is a serious progressive condition with a poor prognosis if it is not identified and treated early [3].

PAH is a common complication of CHD, and most often occurs in patients with a ventricular septal defect (VSD) [4]. Cardiac surgical patients presenting with pre-existing PAH are at a higher risk for postoperative complications than those without PAH [5]. Additionally, the mortality rate of children with both VSD and PAH is 2.6 times higher than those without PAH. It is important to note that the morbidity rate of children with PAH is much higher in China than western countries, perhaps due to imperfect medical conditions, in which many children are not diagnosed until they have obvious symptoms [6].

CHD presents medical management challenges throughout the lifespan of the patient [7]. Recently, the transition from hospital care to home care has added a huge burden for the families caring for their children [8], and the child's rehabilitation can be affected by the caregiver's skillset [9]. In China, nurses and doctors rarely keep track of the children after they are discharged and rarely offer interventions for mothers caring for these children at home [10]. Discharge education is typically provided on the day of discharge. However, asking parents to absorb and comprehend all of the information about how to care for their children in this brief interval can be challenging [11]. Discharge planning, as an extension of the nursing service, can help to deliver patient-centered care to patients' homes [12]. Many studies about discharge planning in pediatric nursing have shown that it can improve maternal confidence and maternal caring knowledge before discharge, reduce the readmission rate of the children, and promote a mother's caring competency [13–16].

For this study, we hypothesized that the discharge preparation, maternal caring knowledge and maternal caring behavior of mothers in the intervention group will be higher than that in the control group. This increased preparedness will then be reflected with a decreased rate of readmission in the intervention group. The results of our study confirmed the first part of this hypothesis.

## 2. Methods

### 2.1. Ethical considerations

This study has been carried out in accordance with *The Code of Ethics of the World Medical Association*. Formal written consent

was obtained from each participant before data collection. Participants could quit the study at any time.

### 2.2. Study population

This study was conducted in a first-class hospital specialized to treat cardiovascular disease in China, using a quasi-experimental design. The sample size was calculated using a pairwise t-test based on Yang's study. Additional patients were included to account for attrition. We recruited 60 children with VSD with PAH and their mothers, with 30 mother–child pairs in the control and 30 in the intervention group. In order to avoid cross contamination, participants in the intervention group were enrolled from June to August, 2013, and the participants in the control group were recruited from September to November, 2013.

The inclusion criteria for children were: 1) medical diagnosed of VSD with PAH; 2) without other congenital defects; 3) 0–6 years of age; and 4) neither of the parents were healthcare professionals. The inclusion criteria for mothers were: 1) primary caregiver of the children; 2) capable of communicating in Chinese; and 3) without any cognitive disability.

### 2.3. Intervention

Mothers in the control group received the discharge service currently offered as the standard of care. This discharge service included education from the charge nurse on the day of discharge regarding how to take any prescribed medication after they return home.

The discharge planning service for the mothers in the intervention group included two phases: (1) in the hospital: six one-on-one lessons in the afternoon with the aid of an education booklet, starting on the day of admission, and daily over the course of the time they were in the hospital; (2) after discharge: follow up was provided by researchers via telephone calls at one week, one month, two months, and three months after discharge. During these phone calls, researchers provided additional counseling and advice.

During the first phase in the hospital, every training session of every mother was recorded, and we ensured that all content of the trainings were mastered by the mothers. If a mother did not have time one afternoon, the class was delayed until the next afternoon. The educational contents covered six parts: (1) The structure of a normal heart, the abnormal structure of their child's heart and how the doctors are going to treat the child, 30 min. (2) Tips for physical activity, which include activity intensity, patterns of activity and how to choose an activity place for children after discharge, 30 min. (3) How to feed the child after surgery, how to choose appropriate food for the child, and how to adjust the intake volume when the child has a fever, 40 min. (4) How to bath the child after surgery, how to prevent infection, how to use the pigeon breast therapeutic apparatus (an instrument to prevent pigeon breast deformity after open heart surgery for children) and scar tissue, 40 min. (5) The effects and side effects of the drugs, and how to take them, 40 min. (6) What to do when the child has a fever or diarrhea, and when to see the doctor, 30 min. After each class, a researcher asked questions to evaluate the educating effect. Mothers who answered 90%

of the questions were considered to have mastered the content. Additionally, mothers were given a chance to ask additional questions that were not included in the classes.

During the second phase after discharge, mothers were given access to the researcher to ask for help any time they encountered a problem. Additionally, the researcher contacted the mothers via telephone at specific time points to inquire about the child's condition and resolve any issues. These calls were made at one week, one month, two months, and three months after discharge.

## 2.4. Instruments

### 2.4.1. Follow-up questionnaire

The questionnaire was developed for this study by researchers to record the rehospitalization of the children one month and three months after discharge. Mothers were asked to record the time and reasons for rehospitalization and mail the form back to the researcher.

### 2.4.2. Questionnaire for knowledge of home care for a child with VSD and PAH

The questionnaire for knowledge of home care for a child with VSD and PAH was developed by researchers based on the one utilized by Yang, who developed a similar questionnaire testing the knowledge of home care for infants with CHD) [16]. The questionnaire that we developed was used to measure maternal caring knowledge in this study, and included questions relating to the basic knowledge of the heart, how and what to feed the children after surgery, appropriate physical activity after surgery, how and when to take medicines after discharge, and caring for the incision site. In this study, the content validity index (CVI) of each item was 0.83–1 and the CVI of the whole questionnaire was 0.99. Overall internal consistency, as measured by Cronbach's  $\alpha$ , was 0.72. The scale includes 20 questions and one point for each question. Therefore, the full marks were 20 and the possible lowest score was 0. Higher scores reflect a higher level of knowledge.

### 2.4.3. Questionnaire of maternal behavior in home care for child with VSD and PAH

The behavior questionnaire, which assessed the follow-through of mothers in enacting the recommended home care for child with VSD and PAH, was developed by researchers. The behavior questionnaire asked questions which addressed feeding after surgery, activity after surgery, medication administration after discharge, incision care and prevention of infection. In this study, the CVI of each item and the whole questionnaire was 0.83–1 and 0.97, respectively. Internal consistency of the overall questionnaire, as measured with Cronbach's  $\alpha$ , was 0.74. The questionnaire consisted of twenty questions appraising the mother's behaviors while caring for their child with VSD and PAH at home. The scale includes 20 questions and use a Likert-3 scoring method. Therefore, the full marks were 60 and the lowest possible score was 20. A higher score indicates better behavior of home care.

### 2.4.4. Discharge readiness scale

Previously, linear analogue scales have been shown to quantitatively measure a global evaluation of a given event in a

reliable and valid manner [17]; therefore, we developed the discharge readiness scale for our study based on The Comfort Readiness Linear Analogue Scale in Stinson's study [17]. The discharge readiness scale was used to appraise maternal discharge readiness. Mothers were asked to mark the point on a 100 mm line that reflected how ready they were to care for their children at home. The top of the scale (100 mm) represented feeling extremely ready and the bottom (0 mm) represented feeling not ready at all.

### 2.4.5. Education booklet

The education booklet was written by the researchers after a qualitative investigation of current patients [18], and referring to related literature which was about discharge planning of children with congenital heart disease and the nursing instructions after discharge [16,17,19–22]. The qualitative investigation indicated that mothers of CHD children had three major needs after discharge: professional guidance, knowledge of caring, and social support. The knowledge of caring included knowledge about surgical incision nursing and feeding, taking medicines, and activity tips. The education booklet was provided by researchers for all mothers, including those in the control group. For the intervention group, this booklet was used as an aid during the classes.

## 2.5. Data collection

Data was collected from June to November in 2013. The purpose and procedures of the study were explained to all the participants. Written consent was obtained from all the mothers. The demographic information was collected and maternal caring knowledge was assessed after admission. Before discharge, we evaluated maternal caring knowledge and maternal caring behavior, as well as maternal discharge readiness.

On the day of discharge, the researcher gave mothers two stamped envelopes with questionnaires to be completed and returned one month and three months later, which including both questionnaires on maternal caring knowledge and maternal caring behavior, as well as the questionnaire regarding any rehospitalization of their child. At the corresponding time-points, one month and three months after discharge, the researcher would remind the mothers to mail back the envelopes by telephone.

## 2.6. Data analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS), version 18.0 (SPSS Inc., Chicago, IL, USA). Statistical methods included descriptive statistics, t-test, Chi-square test, rank test, and repeated measures analysis of variance (ANOVA). Significance for data analysis was set at  $p < 0.05$ .

## 3. Results

### 3.1. Retention and attrition of subjects

Efforts were made to contact mothers by telephone who did not mail back the questionnaires at one month and three

months after discharge. One mother did not want to mail back the questionnaire at either time-point after discharge. Two mothers that did not mail back the three-month follow-up questionnaires had changed their telephone numbers and could not be contacted. The final rates of follow-up were 98.33% and 95% at one and three months after discharge, respectively.

### 3.2. Demographic characteristics of subjects

Table 1 shows the demographic data of the subjects. No significant differences were detected between the children in the two groups in terms of age or the duration of hospitalization. Additionally, the maternal demographic characteristics were also similar. The majority of mothers had a low education level, were from poor economic conditions and lived in a rural area.

### 3.3. Effectiveness of the intervention

Maternal discharge readiness was evaluated by the discharge readiness scale, and the results were analyzed using a t test to compare differences between the two groups. Mothers in the intervention group rated significant higher scores than those in the control group ( $t = 3.35, p = 0.001$ ; Table 2).

Maternal caring knowledge was measured by the questionnaire for knowledge of home care for child with VSD and PAH. No statistical difference was detected in the score of maternal knowledge after admission between the two groups, as both groups lacked caring knowledge at this time-point (10.9 vs. 9.8,  $t = 1.49, p = 0.141$ ; Table 2). A repeated measures ANOVA was used to analyze changes in knowledge throughout the course of the study, and the intervention group scored significantly higher over time than those of the

control group ( $F = 84.74, p < 0.0001$ ; Table 3). Additionally, maternal caring knowledge was significantly higher in the study group than the control group at all times assessed, including at discharge, and one and three months after discharge ( $t = 12.60, p < 0.0001$ ;  $t = 6.44, p = 0.000$ ;  $t = 5.95, p < 0.0001$ ; Table 2).

Maternal caring behavior was measured by the questionnaire of maternal behavior in home care for child with VSD and PAH. According to results of repeated measures ANOVA, mothers in the intervention group had significantly higher scores than those in the control group ( $F = 23.82, p = 0.000$ ; Table 4). Additionally, mothers in the intervention group scored higher than mothers in the control group at discharge, and at one and three months after discharge ( $t = 4.81, p < 0.0001$ ;  $t = 2.90, p = 0.006$ ;  $t = 3.43, p = 0.001$ ; Table 2).

One month after discharge, the readmission rate was 24.1% in the control group and 16.7% in the intervention group. In the control group, five children were hospitalized with pneumonia, and three of those were admitted a second time. In the intervention group, one child was readmitted to hospital with a high fever, while four other children were hospitalized with pneumonia. Three months after discharge, the readmission rate of the control group was 14.3%. However, the readmission rate in the intervention group was 0%. In the control group, four children were readmitted with pneumonia. However, no statistical difference was detected in the readmission rate between two groups at either time point (Table 2).

## 4. Discussion

In our study, the median age of the children was 8 months in intervention group, and 10.5 months in the control group. Among the 60 children in the study, 41 were under one year of

**Table 1 – Characteristics of subjects.**

| Variable                       | Intervention group (n = 30)<br>Median (interquartile<br>range)/n(%) | Control group<br>(n = 30) median<br>(interquartile range)/n(%) | Z/X <sup>2</sup> | p     |
|--------------------------------|---|--|------------------|-------|
| Age of children (months)       | 8.0 (6.0, 11.3)   | 10.5 (6.0, 18.8)   | -1.18            | 0.238 |
| Gender                         |   |  | 1.07             | 0.438 |
| Male                           | 12 (40.0)   | 16 (53.3)  |                  |       |
| Female                         | 18 (60.0)   | 14 (46.7)  |                  |       |
| Hospital stay (days)           | 11.0 (8.8, 14.0)  | 12.0 (9.0, 15.3)   | -0.43            | 0.667 |
| Age of mothers (year)          | 27.0 (25.0, 31.0)   | 29.0 (26.0, 32.0)  | -1.01            | 0.313 |
| Education level of mothers     |   |  | 1.04             | 0.792 |
| Junior high school             | 13 (43.3)   | 12 (40)  |                  |       |
| High school                    | 10 (33.3)   | 10 (33.3)  |                  |       |
| Bachelor degree junior college | 7 (23.3)  | 7 (23.3)   |                  |       |
| Master degree or higher        | 0 (0)   | 1 (3.3)  |                  |       |
| Family income (RMB/month)      |   |  | 3.08             | 0.378 |
| <1500                          | 10 (33.3)   | 8 (26.7)   |                  |       |
| 1500–2999                      | 11 (36.7)   | 8 (26.7)   |                  |       |
| 3000–5999                      | 5 (16.7)  | 11 (36.7)  |                  |       |
| ≥ 6000                         | 4 (13.3)  | 3 (10.0)   |                  |       |
| Residence area                 |   |  | 0.00             | 1.000 |
| Urban                          | 24 (40.0)   | 12 (40.0)  |                  |       |
| Rural                          | 36 (60.0)   | 18 (60.0)  |                  |       |

**Table 2 – Difference in maternal discharge readiness, maternal caring knowledge, maternal caring behavior and readmission of children between intervention and control groups.**

| Indicators                       | Intervention group<br>mean (SD) | Control group<br>mean (SD) | t/X <sup>2</sup> | p       |
|----------------------------------|---------------------------------|----------------------------|------------------|---------|
| Maternal discharge readiness     | 75.9 (19.0)                     | 56.7 (25.0)                | 3.35             | 0.001   |
| <b>Maternal caring knowledge</b> |                                 |                            |                  |         |
| After admission                  | 10.9 (2.9)                      | 9.8 (2.6)                  | 1.49             | 0.141   |
| Before discharge                 | 19.3 (1.1)                      | 11.8 (3.1)                 | 12.60            | <0.0001 |
| 1 month after discharge          | 19.4 (0.8)                      | 16.5 (2.3)                 | 6.44             | <0.0001 |
| 3 months after discharge         | 19.5 (0.8)                      | 16.7 (2.3)                 | 5.95             | <0.0001 |
| <b>Maternal caring behavior</b>  |                                 |                            |                  |         |
| Before discharge                 | 57.3 (2.2)                      | 52.1 (5.5)                 | 4.81             | <0.0001 |
| 1 month after discharge          | 58.2 (2.1)                      | 55.8 (3.9)                 | 2.90             | 0.006   |
| 3 months after discharge         | 57.5 (2.6)                      | 53.8 (5.1)                 | 3.43             | 0.001   |
| <b>Readmission of children</b>   |                                 |                            |                  |         |
| Non-readmission (1 month)        | 25                              | 24                         | 0.34             | 0.561   |
| Readmission (1 month)            | 5                               | 7                          |                  |         |
| Non-readmission (3 months)       | 29                              | 24                         |                  | 0.052   |
| Readmission (3 months)           | 0                               | 4                          |                  |         |

age and 17 children were between one and three years of age. Only two of the children were older than three years of age, as most children with PAH are operated on at a young age. About 60% of the children in this study came from rural areas. These mothers, in particular, needed extra help with the discharge instructions.

Our results showed that the maternal discharge readiness in intervention group was much higher than that in control group. These results were similar to Marianne et al.'s study, which found the quality of discharge teaching, particularly the nurses' teaching skills, was associated with increased parental readiness for discharge [23]. In order to improve the maternal discharge readiness in our study, researchers taught mothers one-on-one, and provided mothers with an education booklet containing the nursing instructions. The results of our study indicate that this method was quite effective.

Researchers also followed up the mothers on telephone and provided them with additional nursing instructions for any issues that came up one week, one month, two months, and three months after discharge. This intervention increased maternal caring knowledge scores on the questionnaire significantly as compared to the control group. Additionally, we found this knowledge improved over time. In contrast, a previous study by Yang et al. did not see significant improvement in knowledge over time [16]. However, the infants in that study had different types of CHD, as compared to all the children in our study, which had the same types of CHD. This might account for the differences in our results.

Discharge planning also improved maternal caring behavior in our study. This is similar to a previous study of 32 parents of children with CHD. In this study, they found that

after a two-phase discharge planning, parental care practice (PCP) scores were increased as compared to controls [15].

These differences in maternal discharge readiness, maternal knowledge and maternal caring behavior were unfortunately not reflected in readmission rates, which were not statistically different. However, because the readmission rate was slightly lower in intervention group than that in control group, it is possible that increasing the sample size or increasing the follow-up time might make these results more statistically significant.

Another caveat to our study was that the children in our study were most frequently readmitted for pneumonia, which was different from Mackie et al.'s study that found that the most common reason for readmission were cardiac (59%) and respiratory illness (12%) [24].

Overall, the results of our studies indicated that discharge planning could be very beneficial for both the parents and the children. Additional studies are needed to further elucidate the benefits of developing discharge planning for children with CHD-PAH, as well as to improve on the educational tools employed in this study.

#### 4.1. Limitations

There are four major limitations of this study. First, the data of the two groups were not collected at the same time. It was necessary to prevent the mothers from comparing information and ensuring a more clear result for our study, as in this ward of our hospital, three children share one room. The second limitation was the length of follow-up in this study. We did not follow participants beyond three months after

**Table 3 – Repeated-measures analysis of variance of maternal caring knowledge score.**

| Variable           | Admission  | Before<br>discharge<br>mean(SD) | 1 month after<br>discharge<br>mean(SD) | 3 months after<br>discharge<br>mean(SD) | Between<br>groups |         | Within group |         | Time & group |         |
|--------------------|------------|---------------------------------|--|---|-------------------|---------|--------------|---------|--------------|---------|
|                    |            |                                 |  |   | F                 | p       | F            | p       | F            | p       |
| Intervention group | 10.9 (2.9) | 19.3 (1.1)                      | 19.4 (0.8)                             | 19.5 (0.8)                              | 84.74             | <0.0001 | 206.41       | <0.0001 | 28.36        | <0.0001 |
| Control group      | 9.8 (2.6)  | 11.8 (3.1)                      | 16.5 (2.3)                             | 16.7 (2.3)                              |                   |         |              |         |              |         |

**Table 4 – Repeated-measures analysis of variance of maternal caring behavior score.**

| Variable           | Before discharge<br>Mean(SD) | 1 month after<br>discharge<br>Mean(SD) | 3 months after<br>discharge<br>Mean(SD) | Between group |         | Within<br>group |       | Time&<br>group |       |
|--------------------|------------------------------|--|---|---------------|---------|-----------------|-------|----------------|-------|
|                    |                              |  |   | F             | p       | F               | p     | F              | p     |
| Intervention group | 57.3 (2.2)                   | 58.2 (2.1)                             | 57.5 (2.6)                              | 23.82         | <0.0001 | 8.30            | 0.002 | 2.59           | 0.102 |
| Control group      | 52.1 (5.5)                   | 55.8 (3.9)                             | 53.8 (5.1)                              |               |         |                 |       |                |       |

discharge, therefore, it was not known that how long the effectiveness of our intervention would continue. The third limitation was that the data were all collected from one hospital, which might affect the representative sample. Finally, the sample size was smaller than ideal due to limitations of time and manpower, which might be the reason for negative results in the difference of readmission rate.

## 5. Conclusion

Discharge planning improves the maternal discharge readiness, maternal caring knowledge and maternal caring behavior. This improvement lasted for at least three months, and suggests that providing a discharge planning service can help mothers increase the quality of their home nursing care. Although discharge planning has no significant effect in decreasing the readmission rate of children after discharge, further research is needed to test the effectiveness of discharge planning on readmission rate of children.

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