

Case Management Implications for Pediatric Patients With Congenital Heart Disease in China: A Randomized Controlled Trial

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Abstract

Objectives. Case management, which is defined as a fully collaborative process that includes evaluation, planning, execution, coordination and supervision, has been widely used in the field of chronic diseases. However, the clinical effect of case management in pediatric patients with congenital heart disease (CHD) is unclear. This study was to explore the effects of case management model in pediatric patients with CHD. **Methods.** A total of 110 pediatric CHD patients referred to our center from January 2018 to January 2020 were enrolled for analysis. Patients were randomly assigned to a case management (experimental) group or a conventional nursing (control) group. Patient satisfaction, quality of life, and clinical outcomes were compared between the 2 groups. **Results.** Compared with that in the control group, patient satisfaction rate was significantly greater in the experimental group. Furthermore, the experimental group showed more significant improvement in quality of life than the control group did (73.8 ± 12.3 vs 66.5 ± 14.2 , $P < .001$). In addition, the readmission rate in the experimental group was significantly lower than that in the control group (5% vs 20%, $P = .022$). **Conclusions.** Case management mode can be effectively applied in pediatric patients with CHD, which can improve patient satisfaction rate, health-related quality of life and lower the readmission rate.

Keywords

case management, congenital heart disease, quality of life, readmission

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Introduction

Congenital heart disease (CHD) is the most common type of congenital malformations, which causes a huge burden to the family and society.¹ According to a Maternal and Child Surveillance report, the overall prevalence of CHD in China is 17.3 per 1000 live births.² Without early diagnosis and treatment, up to 60% of babies with complex CHD die from severe complications after birth.³ Furthermore, many CHD children often need rehospitalization after birth due to the poor heart condition. The family's demand for treatment information, psychological support and rehabilitation nursing care is increasing during the long-term treatment procedure. A lack of relevant information may affect the prognosis of the CHD children.⁴ A hierarchical three-level prevention and treatment network has been established in China. In this network, certified primary obstetric medical institutions are responsible for

screening; provincial and municipal tertiary maternal and child health hospitals, and obstetric departments in general hospitals are responsible for diagnosing the CHD subtype; and regional or national clinical research centers with pediatric cardiac departments provide consultation services for complex CHD cases and support with decision making.⁵ However, establishing an effective management system of CHD is still challenging in China due to the uneven medical level, low prenatal diagnosis rate and insufficient postnatal follow-up

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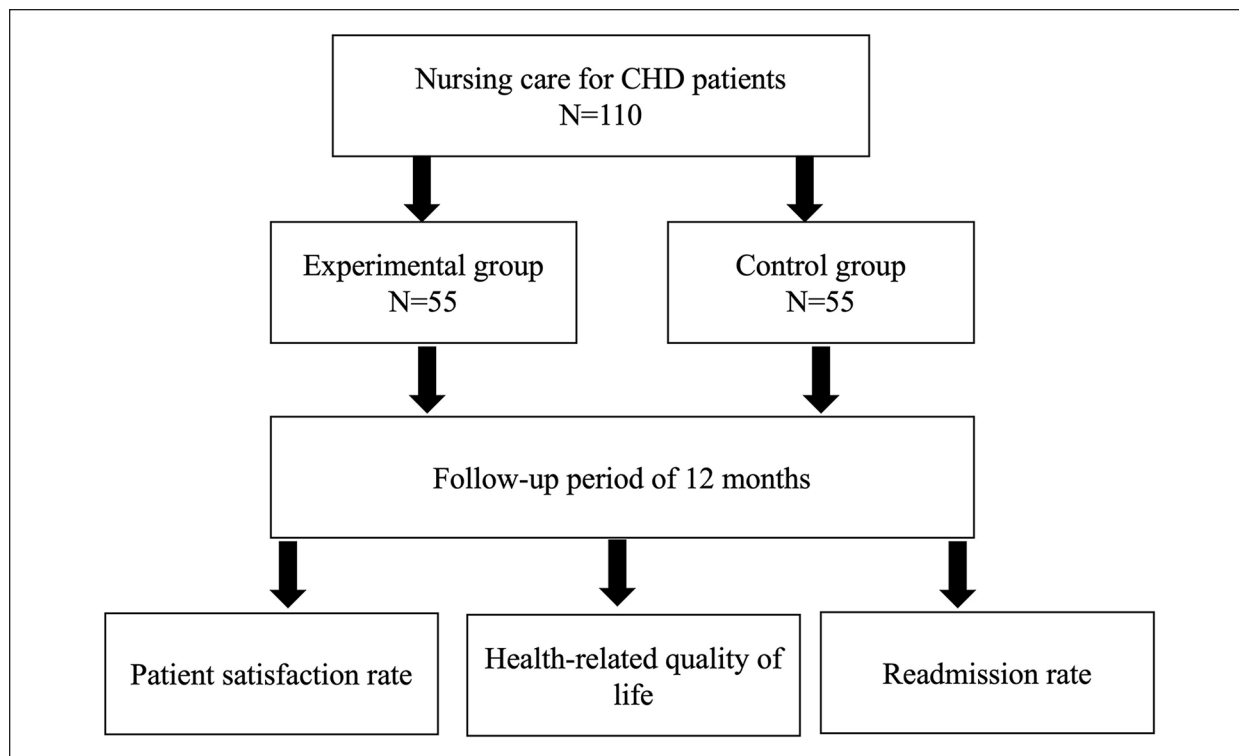


Figure 1. Flowchart of patients with congenital heart diseases enrolled in this study.

management. The demand for coordinating and utilizing the limited care resources to provide high-quality health care services for CHD children is increasing. Case management is conducted by case managers and a multidisciplinary medical team to provide the whole medical course and individualized consultation and guidance, and ensure the maximum equity of the treatment process.⁶ Case management has been widely used in the field of many chronic diseases, which has fully shown its advantages.⁷⁻⁹ However, the clinical effect of case management in pediatric patients with CHD is unclear. This study was to explore the effects of case management model in pediatric patients with CHD.

Methods

Study Design and Population

This study was designed as a single-center, randomized controlled trial (ChiCTR2000039544, including some patients from our previous study¹⁰). The CHD pediatric patients admitted in Guangzhou Women and Children Medical Center from January 2018 to January 2020 were enrolled for analysis. The inclusion criteria were as follows: (1) Patients met the diagnostic criteria for CHD; (2) The age of the patient ranged from 2 to 4 years; (3) The families of the patients were willing to participate in this

study and sign the consent form. The exclusion criteria were as follows: (1) Major developmental delay that could affect health-related quality of life; (2) The patients or families had mental abnormalities, language communication or hearing impairment. The patients were randomly assigned to 2 groups on the basis of nursing management: patients receiving conventional nursing care were assigned to the control group, and patients receiving case management nursing care were assigned to the experimental group (Figure 1). Randomization was performed on the basis of a random number generator.

Ethical Approval and Informed Consent

This study was approved by the institutional ethics committee of Guangzhou Women and Children Medical Center (No.2018-025). Written parental consent was obtained from all participants.

Conventional Nursing

Routine nursing care was performed in the control group. During the period of hospitalization, nursing care and health education were conducted by the responsible nurse. After hospital discharge, the patients were routinely guided by the responsible nurse and followed up at 1, 3, 6, and 12 months. The medical follow-up team

Table 1. Specific Content of Case Management Intervention.

Stage	Content
Assessment	<ul style="list-style-type: none"> • Round and review patient medical records daily • Discuss the patient's condition and detailed care plan via MDT
Planning	<ul style="list-style-type: none"> • Initiate contact with the patient family • Introduce to the case management program
Implementation	<ul style="list-style-type: none"> • Watch the video with the patient family displaying: <ul style="list-style-type: none"> ▪ how to do feeding after procedure ▪ wound care ▪ management of physical symptoms ▪ coping with psychological reactions ▪ social recourses ▪ rehabilitation • Provide the home care handbook that summarizes key points from the video • Encourage the patient family to ask questions about the content of the instruction materials • Discuss the rehabilitation plan with the family • Distribute the patient satisfaction questionnaire
Evaluation	<ul style="list-style-type: none"> • Contact the patient family at the follow-up time points • Inquire quality of life using PedsQL Cardiac Module

Abbreviations: CHD, congenital heart disease; MDT, multidisciplinary team; PedsQL, Pediatric Quality of Life.

regularly queried the patient's recovery status and provided guidance on follow-up plans, medication adherence, and rehabilitation training.

Case Management

The experimental group adopted a case management model. The admission, discharge and follow-up visits were performed in strict accordance with the case management schedule. The case management intervention was a multidisciplinary and nurse-led program in this study. The multidisciplinary team (MDT) included cardiologist, cardiac surgeon, perfusionist, anesthesiologist, cardiac sonographer. Specialized nurse (L.Z.) who has been trained and qualified with at least 5 years of clinical nursing experience in CHD was selected as a full-time case manager responsible for coordinating and collaborating on medical resources, providing a continuous medical care plan, consulting services and psychological support for patient families. Table 1 shows the specific content of the case management intervention.

Data Collection

Demographic and clinical data and the patient satisfaction questionnaire were collected by the nurse case manager (L.Z.) before hospital discharge. Follow-up visits were performed at 1, 3, 6, and 12 months after hospital discharge via telephone interviews or face to face interviews at the outpatient clinic. Quality of life was accessed at the 12-month follow-up time point via the Chinese version of Pediatric Quality of Life (PedsQL)

3.0 Cardiac Module. Readmission was carefully accessed by the medical team during the follow-up visit. If the patient was admitted for CHD-related complications such as heart failure, pneumonia, arrhythmias, or myocarditis, readmission was considered.

Measurement

The patient satisfaction questionnaire is a self-developed unified, 4-item scale that provides a rapid assessment of medical care (Supplemental Appendix 1). Following a review of the pertinent literature, the researchers extended the invitations to 4 experts with expertise in nursing, pediatric diagnosis, treatment, and management. These experts were engaged to evaluate and refine the preliminary version of the questionnaire prior to the actual experiment. Subsequently, the questionnaire underwent revisions based on their feedback, with a focus on enhancing its reliability and validity. The fourth item used in this study addressed the following dimensions: medical healthcare, nursing care, medical charge and workflow efficiency. It is scored on a 5-point Likert scale from 0 to 4 (0=very dissatisfied, 1=dissatisfied, 2=neutral, 3=satisfied, 4=very satisfied) with a possible score ranging from 0 to 16. Higher scores are related to higher satisfaction on all scales.

The reliability and validity of Chinese version of the PedsQL 3.0 Cardiac Module have been validated in previous studies.^{11,12} Therefore, the PedsQL 3.0 Cardiac Module, which was translated and adapted to the Chinese language, was used to assess health-related quality of life by parental report.¹³⁻¹⁵ The PedsQL 3.0 Cardiac

Table 2. Baseline Characteristics Between the 2 Groups.

Variable	Experimental group (n=55)	Control group (n=55)	P value
Age (months)	32 ± 12	33 ± 15	.35
Male (%)	24 (43.6%)	27 (49.1%)	.57
Weight (kg)	12.3 ± 1.3	11.9 ± 1.6	.42
Congenital heart diseases (%)			
Ventricular septal defect	14 (25.5%)	16 (29.1%)	.67
Atrial septal defect	3 (5.5%)	2 (3.6%)	.65
Atrioventricular septal defect	4 (7.3%)	3 (5.5%)	.70
Transposition of the great arteries	7 (12.7%)	5 (9.1%)	.54
Total anomalous pulmonary venous connection	3 (5.5%)	6 (10.9%)	.49
Coarctation of aorta	5 (9.1%)	4 (7.3%)	.73
Tetralogy of fallot	8 (14.5%)	9 (16.4%)	.79
Others	11 (20%)	10 (18.2%)	

Module is a disease-specific module and has 23 items in 6 domains measuring the frequency of disease-related problems and severity of negative emotions about these by proxy report: heart problems (7 items), treatment (3 items), perceived physical appearance (3 items), treatment anxiety (4 items), cognitive problems (3 items), and communication (3 items). The parent-proxy report forms parents are asked to evaluate their child's quality of life. Five answer options are listed in the PedsQL (0=it is never a problem; 1=it is almost never a problem; 2=it is sometimes a problem; 3=it is often a problem; and 4=it is almost always a problem). As to the scoring, answer options must be transformed as follows: 0=100; 1=75; 2=50; 3=25; and 4=0. Higher scores represent higher health-related quality of life in all scales. The sum of all the items over the number of items answered provides a mean score.

Statistical Analysis

All continuous variables are presented as the means ± standard deviations. The categorical variables are presented as numbers and percentages. Categorical variables were compared using χ^2 analysis. Continuous variables were compared using the Student's *t*-test or Mann–Whitney *U* test, depending on data distribution. A two-tailed value of $P < .05$ was considered statistically significant. All statistical analyses were performed using SPSS 26.0 (SPSS, Chicago, IL, USA).

Results

Patient Characteristics

A total of 110 pediatric patients who met the inclusion and exclusion criteria were randomized into 2 groups: 55 in

Table 3. Comparison of Patient Satisfaction Rate Between the 2 Groups.

Scale	Experimental group (n=55)	Control group (n=55)	P value
Medical health care	14.5 ± 1.2	11.3 ± 2.3	.032
Nursing care	14.1 ± 1.3	11.6 ± 0.7	.021
Medical charge	12.7 ± 2.1	12.9 ± 2.5	.523
Workflow efficiency	14.5 ± 1.6	12.3 ± 1.7	.029

conventional nursing group and 55 in case management group. The detailed patient characteristics are described in Table 2. No significant differences in age, gender, and heart diseases status were found between the 2 groups.

Patient Satisfaction Questionnaire

Compared with the control group, the experimental group showed higher satisfaction rate in medical health-care (14.5 ± 1.2 vs 11.3 ± 2.3, $P = .032$), nursing care (14.1 ± 1.3 vs 11.6 ± 0.7, $P = .021$), and workflow efficiency (14.5 ± 1.6 vs 12.3 ± 1.7, $P = .029$). There was no significant difference between the two groups in the dimensions of medical charge (12.7 ± 2.1 vs 12.9 ± 2.5, $P = .523$; Table 3).

Health-related Quality of Life

The PedsQL 3.0 Cardiac Module scores are shown in Table 4. The experimental group had higher total scores compared with the control group (73.8 ± 12.3 vs 66.5 ± 14.2, $P < .001$). Furthermore, higher scores in dimensions of treatment (82.1 ± 16.5 vs 68.6 ± 15.3, $P < .001$), perceived physical appearance (75.3 ± 11.4 vs 65.4 ± 13.1, $P = .004$), and treatment anxiety (80.2 ± 10.3

Table 4. Comparison of Quality of Life Between the 2 Groups.

Scale	No. items	Experimental group (n=55)	Control group (n=55)	P value
Total	23	73.8 ± 12.3	66.5 ± 14.2	<.001
Heart problems	7	75.4 ± 18.3	70.3 ± 17.5	.112
Treatment	3	82.1 ± 16.5	68.6 ± 15.3	<.001
Perceived physical appearance	3	75.3 ± 11.4	65.4 ± 13.1	.004
Treatment anxiety	4	80.2 ± 10.3	70.8 ± 15.2	.003
Cognitive problems	3	66.2 ± 24.2	63.5 ± 19.3	.243
Communication	3	63.4 ± 15.7	60.3 ± 16.7	.421

vs 70.8 ± 15.2 , $P=.003$) were observed in experimental group than in control group. No significant differences were found in dimensions of heart problems, cognitive problems, and communication between 2 groups.

Follow-up

During the follow-up period of 12 months, 11 of 55 (20%) patients in control group experienced readmissions, including 5 patients with heart failure, 4 with pneumonia, and 2 with tachyarrhythmia, whereas only 3 of 55 (5.5%) patients in experimental group experienced readmissions, including 2 patients with heart failure and 1 with pneumonia ($P=.022$).

Discussion

The present study described the clinical effect of case management model in pediatric patients with CHD. In this study, we found that case management mode can be effectively applied in pediatric patients with CHD during a follow-up period of 12 months, which can improve patient satisfaction rate and quality of life and lower the readmission rate.

CHD is the most common birth defect. According to the epidemiological research, the worldwide prevalence of CHD is 8 to 9 per 1000 live births,¹⁶ however, the overall prevalence of CHD in China is 17.3 per 1000 live births.² The children with CHD often have a long treatment course and need repeated hospitalization after birth due to the poor heart conditions, which may lead to irregular follow-up, negative treatment and heavy economic burden to the families. Patients with CHD have complex health care needs that often must be provided for or coordinated for by the medical team.¹⁷ However, establishing an effective management system for CHD is still challenging in China due to the uneven medical level, low prenatal diagnosis rate and insufficient post-natal follow-up management.⁵

Since the case management was firstly launched in patients with breast cancer in the UK in the 1970s, it has

been widely used in various chronic diseases, such as cancer, chronic heart failure, diabetes, and fully demonstrated its advantages.^{8,18,19} However, reports concerning case management in the treatment of pediatric patients with CHD are limited. In this study, case management model was effectively applied in the care of the CHD patients, which can support the whole course of the CHD management, help children and families reduce the risk of readmission, and improve the quality of life.

Our findings revealed that the patient satisfaction rate was significantly higher in patients who received case management than in those who received conventional nursing care. Case manager established stable cooperative relationships with families and medical teams. The effective communication between the case manager and the families of the children enabled the families to gain a clear understanding of the entire perioperative and post-hospital follow-up process. Moreover, for quality of life, the experimental group was associated with higher total scores than the control group (73.8 ± 12.3 vs 66.5 ± 14.2 , $P<.001$), which indicated that the health-related quality of life was superior in pediatric patients with case management model than in those without it. Furthermore, higher scores in dimensions of treatment (82.1 ± 16.5 vs 68.6 ± 15.3 , $P<.001$), perceived physical appearance (75.3 ± 11.4 vs 65.4 ± 13.1 , $P=.004$), and treatment anxiety (80.2 ± 10.3 vs 70.8 ± 15.2 , $P=.003$) were also observed in experimental group than in control group. Case manager plays a vital role in educating, supporting, cooperating and coordinating. In the process of tracking and providing feedback to patient families, the case manager supervised the execution of treatment, the development of a rehabilitation plan for patients, the arrangement of outpatient visits and provided psychological support for patients and families. Another finding of our study was that the readmission rate was significantly lower in patients with case management. This might be explained by the timely response to patients' discomfort and adjustment of therapeutic plan. Improving the patient's physical and mental state is beneficial for the prognosis of the condition, laying the foundation for overall recovery.

This study has added new knowledge regarding a case management intervention for pediatric patients with CHD in China. The findings support that a case management program has long-term effects in helping patients obtain better quality of life and improving the clinical outcome. This model fully demonstrates the concept of patient-centered and patient-oriented nursing, and truly elucidates the modern holistic concept of nursing. The case management model maximizes the recovery of pediatric patient health and social adaptability, reduces the burden on patient families, improves the relationship with patients and medical staff and optimizes scarce medical resources in China.

Limitations

There are several limitations in this study. This was a single center study with a small sample size. Power analysis for sample size calculation was not performed in this study. Further randomized controlled studies with large sample sizes may be needed to confirm our findings. Furthermore, this study was performed only in the city of Guangzhou. Therefore, we cannot exclude that especially in the more rural areas of China the intervention might be more difficult to perform.

Conclusions

CHD is still the most common birth defect in China. Patients with CHD often have complex health care needs that must be coordinated by the medical team. This study revealed that the case management mode can be effectively applied in pediatric patients with CHD, which can improve patient satisfaction rate, health-related quality of life and lower the readmission rate. Therefore, our findings support that case management program has long-term effects in helping pediatric patients achieve better quality of life and improving their clinical outcome. The case management model maximizes the recovery of pediatric patient health and social adaptability, reduces the burden on patient families, improves the relationship with patients and medical staff and optimizes scarce medical resources in China.

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Author Contributions

LZ: Contributed to conception and design; contributed to acquisition; drafted manuscript; critically revised manuscript;

gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

XC: Contributed to design; contributed to acquisition, analysis, and interpretation; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

ND: Contributed to design; contributed to analysis and interpretation; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

Declaration of Conflicting Interests

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Supplemental Material

Supplemental material for this article is available online.

References

1. Donofrio MT, Moon-Grady AJ, Hornberger LK, et al. Diagnosis and treatment of fetal cardiac disease: a scientific statement from the American Heart Association. *Circulation*. 2014;129:2183-2242.
2. Maternal and Child Health Surveillance of China. Communication column. 2022. Accessed August 10, 2022. <https://www.mchscn.cn/ViewByStages-34/668.html> (in Chinese).
3. Ma K, He Q, Dou Z, et al. Current treatment outcomes of congenital heart disease and future perspectives. *Lancet Child Adolesc Health*. 2023;7:490-501.
4. Scott M, Neal AE. Congenital heart disease. *Prim Care*. 2021;48:351-366.
5. Zhang Y, Wang J, Zhao J, et al. Current status and challenges in prenatal and neonatal screening, diagnosis, and management of congenital heart disease in China. *Lancet Child Adolesc Health*. 2023;7(7):479-489.
6. Woodward J, Rice E. Case management. *Nurs Clin North Am*. 2015;50:109-121.
7. Wang M, Liu Y, Wang C, Wang X. The effect of Maslow's theory-based case management model on the care of stroke patients. *Am J Transl Res*. 2023;15:4932-4941.
8. McCants KM, Reid KB, Williams I, Miller DE, Rubin R, Dutton S. The impact of case management on reducing readmission for patients diagnosed with heart failure and diabetes. *Prof Case Manag*. 2019;24:177-193.
9. Burton J, Murphy E, Riley P. Primary immunodeficiency disease: a model for case management of chronic diseases. *Prof Case Manag*. 2010;15:5-10, 12-14; quiz 15-16.
10. Zhang L, Shi H, Li J, et al. Optimal frequency for changing single-use enteral delivery sets in infants after congenital

- heart surgery: a randomized controlled trial. *J Am Nutr Assoc.* 2022;41:140-148.
11. Chang Y, Luo Y, Zhou Y, et al. Reliability and validity of the chinese mandarin version of pedsQL™ 3.0 transplant module. *Health Qual Life Outcomes.* 2016;14:142.
 12. Huang YC, Chen YC, Gau BS, Wang JK, Chang SH, Yang HL. Psychometric evaluation of the traditional chinese version of pedsQL™ 3.0 cardiac module scale in adolescents with congenital heart disease: reliability, validity, measurement invariance, and adolescent-parent agreement. *Health Qual Life Outcomes.* 2023;21:39.
 13. Niemitz M, Seitz DC, Oebels M, et al. The development and validation of a health-related quality of life questionnaire for pre-school children with a chronic heart disease. *Qual Life Res.* 2013;22:2877-2888.
 14. Svensson B, Idvall E, Nilsson F, Liuba P. Health-related quality of life in children with earlier surgical repair for right ventricular outflow tract anomalies and the agreement between children and their parents. *Front Cardiovasc Med.* 2020;7:66.
 15. do Nascimento Moraes A, Ramos Ascensao Terreri MT, Esteves Hilario MO, Len CA. Health related quality of life of children with rheumatic heart diseases: reliability of the brazilian version of the pediatric quality of life inventory cardiac module scale. *Health Qual Life Outcomes.* 2013;11:198.
 16. van der Linde D, Konings EE, Slager MA, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. *J Am Coll Cardiol.* 2011;58:2241-2247.
 17. Lantin-Hermoso MR, Berger S, Bhatt AB, et al. The care of children with congenital heart disease in their primary medical home. *Pediatrics.* 2017;140(5):e20172607.
 18. Wang N, Chen J, Chen W, et al. The effectiveness of case management for cancer patients: an umbrella review. *BMC Health Serv Res.* 2022;22(1):1247.
 19. Sadler E, Khadjesari Z, Ziemann A, et al. Case management for integrated care of older people with frailty in community settings. *Cochrane Database Syst Rev.* 2023;5(5):CD013088.