

Original Article

Assessment of the Effect of Family-Centered Care on Anxiety and Care Burden in Parents of Children Undergoing Heart Transplantation

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ABSTRACT

Background: The frequency of organ transplantation is increasing, leading to increased stress in patients and families. Family performance assessment can express psychological and health consequences for children and their families and provide an opportunity for targeted interventions.

Methods: After necessary permits were obtained, the cases were randomly divided into experimental and control groups. Fifty parents of children who underwent heart transplantation participated in the research. Then, after the identification of the subjects in the experimental and control groups, the experimental group was subjected to the family-centered model. Following the completion of the training and 1 month later, anxiety and care-burden questionnaires were distributed to the experimental and control groups. Finally, the data obtained from the questionnaires were collected and analyzed.

Results: Fifty individuals participated in this study. The results of the independent *t* test showed no significant difference concerning anxiety among parents before and after the intervention between the 2 study groups ($P=0.217$). Care burden was less in the intervention group than in the controls ($P=0.039$).

Conclusions: After training, anxiety and care burden in the intervention group improved compared with the control group. Information support of patients' families will help them better adapt to stressful situations. Educating patients and their families can increase their information and reduce their anxiety. (*Iranian Heart Journal 2022; 23(2): 87-95*)

KEYWORDS: Heart transplantation, Anxiety, Care burden, Parents

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Received: September 26, 2021

Accepted: December 11, 2021

Hear failure is a condition in which the heart cannot pump the blood needed by the body for metabolic needs. This clinical syndrome occurs in patients with congenital or acquired defects in the structure or function of the heart and leads to frequent hospitalizations and reduced life expectancy.¹ Recent studies have shown that the rate of mortality due to heart failure is 32%.² The prevalence of heart failure in Iran is 8%, which is high compared with Asian and global statistics.³ Pediatric heart transplantation is standard care for children with end-stage heart failure based on evidence and new technologies. The results are functionally excellent, but there are significant psychosocial challenges related to neurodevelopment, lack of treatment adherence, and transfer from child-centered care to adults. Children's hearts continue to evolve to meet the challenges of a diverse group of patients who have reached the final stages of heart failure in childhood.⁴ The frequency of solid organ transplantation is on the rise, leading to increased stress for patients and families. Further information is needed as regards the psychological and health consequences for children and their families, as well as the provision of opportunities for purposeful interventions.⁵ The severity of the disease, the short attendance time at school, the need for cardiac medications, the parents' income, the uncertain prognosis, the history of cardiopulmonary resuscitation, the number of nights spent in the hospital, and the need for treatment at a care clinic would reduce the quality of life of these children.⁶ Since the introduction of heart transplantation in 1967, there have been many medical advances in pediatric heart surgery that have led to increased survival and improved quality of life.⁷

Future studies should focus not only on assessing psychosocial performance in the post-transplantation years but also on evaluating interventions to improve quality

of life, health-related problems, and child development.⁸ Parents report emergency care responsibilities and concerns following heart transplantation. The child's daily needs after transplantation include medication regimens, blood pressure monitoring, physical exercise, and dietary care.^{9,10}

Parents of children with congenital heart disease (CHD) report high levels of psychological distress and coping problems.¹¹ Parents' ability to cope with psychological adjustments and stress, especially during surgery or other procedures, is vitally important.^{12,13} Parents have reported a wide range of harmful consequences such as underlying stress, communication challenges, isolation, burnout, role changes, and new challenges in the family.¹⁴ Despite the potentially harmful effects on physical and mental health, parents are the key to successful care for their children.¹⁵

Anxiety is high among the parents of children undergoing cardiac catheterization. More anxiety has been reported in the parents of infants and adolescents without a history of a previous catheterization procedure.¹⁶ Parental anxiety is a more important predictor of a child's behavioral outcome than illness or surgical factors.^{17,18} Children and families face different psychological and social challenges in the lifelong challenge of transplanting children's organs.¹⁹ Little is known about the adaptations that families make or the support they need for long-term survival.²⁰ Additionally, heart transplant recipients and their families often experience changing financial and social roles. These changes in their lifestyle occur following heart transplantation.^{21,22}

Family-centered care with improved outcomes for children with special medical needs is recommended by individuals and organizations.²³ Data on anxiety levels are scarce in caregivers of children undergoing cardiac catheterization and related factors. These data are important for family-centered

care and further clinical improvement programs to reduce the level of anxiety in caregivers during the upper stages. Understanding the factors related to the level of anxiety in caregivers is an important step in this process.¹³ An important reason for the development of the concept of family care has been its active promotion by the parents of the children.^{24,25} Family-centered care is a philosophy of healthcare delivery that emphasizes partnerships between providers, patients, and families.²⁶

A care program (support-educational program) is an intervention used to augment the knowledge of caregivers and family members, change attitudes about the nature of problems, bolster support for people in the care position, and boost caregivers' communication skills.²⁷ Given the pressure and depreciation that the care of children induces for parents and the lack of appropriate mechanisms to provide social services to these parents in our country, the present study was conducted to determine the effects of a family-centered care program on anxiety and care burden among the parents of children undergoing heart transplantation.

METHODS

Administrative steps were completed, and the code of ethics was obtained from the ethics committee of the university (code: IRCT20141216020344N2).

The subjects were randomly divided into 2 groups: experimental and control. Initially, the validity of the training materials and questionnaires was confirmed by professors of Iran University of Medical Sciences. The demographic characteristics of the parents and children were extracted via phone calls by transplantation nurses and relevant officials.

Fifty parents of children undergoing heart transplantation cooperated in the research. The education group was divided into 3 subgroups of 7 individuals and 1 group of 4 individuals. According to the desire of each group, the

training time was determined, and the training was performed by sending the materials through virtual training and telephone calls.

After the identification of the subjects in the experimental and control groups, the experimental group was subjected to the family-centered model. Data collection related to the intervention group was done after the coordination and provision of necessary explanations about the study, the introduction of the researcher, the statement of the research objectives, and the completion of the consent form and research questionnaires. After the completion of the research, educational materials were also sent to the control group. After the training and 1 month later, Beck anxiety and Zarit care questionnaires were distributed to the experimental and control groups. Finally, the data obtained from the questionnaires were collected and analyzed.

The family-centered model was performed in 4 stages—namely perceived threat, self-efficacy, educational participation, and evaluation—during 4 sessions of 20 to 40 minutes for the intervention group. According to this model, the first step in the intervention phase was to understand the threat, which in this phase increased the knowledge and awareness of the parents. The second step was problem-solving, which was done to boost the individuals' self-esteem and self-control. In this stage, the parents' knowledge and attitude about the disease were increased, and they participated in care programs. The third step was educational participation, which was measured in 2 stages: at the end of the intervention and 1 month later. Attending meetings and training classes was similar to hospitalization, not caring for another patient at home, and accessing a cell phone. One person in the education group did not continue to cooperate in the third session, one of the parents did not cooperate in the second session, and 2 subjects in the control group did not complete the questionnaires after 1 month. Overall, the data of 25 subjects in the

intervention group and 25 subjects in the control group were analyzed.

The parents were first asked to complete a questionnaire. Then, four 40-minute sessions were performed for 4 consecutive weeks (1 session per week). The parents were informed about common cardiac diseases in childhood, common signs and symptoms, diagnostic methods, and treatment programs, according to the stage and condition of the child's disease; These parents were, thereafter, given basic training in this area and were asked to discuss ways to communicate and exchange views with the hospital treatment team to implement the second phase. In this session, they shared their experiences and information about the treatment, in conjunction with the evaluation and control of the treatment side effects. Other topics that were discussed in this session included ways to prevent infection, pain control and relief, vaccination, self-control enhancement in the face of unhealthy children and their problems, and ways to support other family members.

During the third session, each participant was asked to teach one of their family members in

charge of child care what they had learned in the previous 2 sessions and answer the researcher's questions under his or her indirect supervision. During this session, any possible problem such as forgetting the material or passing on incorrect information by the trained parents was immediately corrected by the researcher. In the fourth session or the final evaluation session, the researcher evaluated all the participants in the intervention group by asking questions about the total content taught and the items discussed in the second and third sessions and finally cleared up the remaining ambiguities.

It is important to note that the subject of the previous session was reviewed by the researcher and at the beginning of each session by asking 1 or 2 questions.

RESULTS

Fifty individuals participated in this study. The distribution of the participants in the 2 groups of intervention and control in terms of graphic information can be observed in Table 1.

Table 1. Distribution of demographic information among the participants in 2 groups

Parameters		Intervention Group	Control Group	Meaning
Sex	Male	(36%) 9	(32%) 8	0.912
	Female	(64%) 16	(68%) 17	
Age, y		32.92±4.76	35.08 ± 4.53	0.917
marital Status	Single	(20%) 5	(12%) 3	.0882
	Married	(72%) 18	(80%) 20	
	Divorced	(4%) 1	(4%) 1	
	Widow	(4%) 1	(4%) 1	
Average number of children		3.01 ± 2.91	4.89 ± 1.82	0.587
Education	Primary school	(4%) 1	(8%) 2	
	Guidance school	(8%) 2	(8%) 2	
	Diploma	(64 %) 16	(60%) 15	
	Higher	(24%) 6	(24%) 6	
Occupation	Self-employed	(32%) 8	(32%) 8	0.98
	Housewife	(40%) 10	(40%) 10	
	Retired	(8%) 2	(16%) 4	
	Employee	(20%) 5	(12%) 3	
Income Level	Down	(12%) 3	(12%) 3	0.908
	Medium	(72%) 18	(68%) 17	
	Top	(12%) 4	(20%) 5	
Location	Rent	(64%) 16	(68%) 17	0.414
	Mortgage	(36%) 9	(32%) 8	
Total		(100%) 25	(100%) 25	

Table 2. Comparison of anxiety among the parents and caregivers between the intervention and control groups before and after training

Parameters	Meaning	Group	Group	Average	Standard Deviation	Minimum	Maximum	Dispute
Anxiety	0.217	Intervention	before	39.771	2.801	31.82	49.223	-4.330
			after	36.302	4.102	30.422	51.201	
	0.161	Control	before	36.602	11.309	30.322	51.507	-6.282
			after	32.171	6.281	32.419	49.311	
Care Burden	0.039	Intervention	before	71.119	3.002	52.414	81.314	-11.811
			after	60.102	3.117	54.401	82.001	
	0.184	Control	before	68.220	1.118	50.201	83.107	-6.607
			after	63.311	6.202	52.411	82.329	

The results of the independent χ^2 and t tests showed no significant differences between the 2 groups in terms of the frequency of demographic information. Female parents were more responsive than their male counterparts. Most parents were married and had a high-school diploma. Housework was the most common job (16%), and the majority of the participants had an average income level (70%). Most parents lived in a mortgaged house (66%).

The Kolmogorov–Smirnov test was used for the inferential analysis of the study variables (Table 2).

Table 2. Determining the normal distribution of anxiety variables and the level of self-care

Parameters	Statistics	Statistics
Anxiety		
before intervention	0.149	0.088
after intervention	0.102	0.123
Care Burden		
before intervention	0.167	0.092
after intervention	0.189	0.054

Based on the results of the Kolmogorov–Smirnov coefficient test on the normal distribution of quantitative variables, both variables had a normal distribution and, therefore, parametric statistical tests were applied to compare them.

Considering the normal distribution of variables in the Kolmogorov–Smirnov test, the paired t test was used (Table 3). As can be seen in the table, the level of anxiety in the intervention group before the

intervention was 39.771, and the standard deviation was 2.801. Nonetheless, after the intervention, this level was 36.302 with a standard deviation of 4.102. In the control group, before the intervention, the level of anxiety was 36.602 with a standard deviation of 11.039. Following the intervention, this level was 32.171 with a standard deviation of 6.281. For the analysis of the relationship between the 2 variables, the paired t test with an α level of 0.05 and a 95% confidence interval was utilized. There was no statistical difference between the intervention and control groups before and after the intervention ($P>0.05$). Therefore, in this respect, the null hypothesis was confirmed. Similarly, the level of care burden in the intervention group was 71.119 with a standard deviation of 3.002 before the intervention. After the intervention, this rate was 60.102 with a standard deviation of 3.117. In the control group, the level of care burden was 68.220 with a standard deviation of 1.118 before the intervention. Following the intervention, this rate was 63.311 with a standard deviation of 6.302. For the analysis of the relationship between the 2 groups, the paired t test with an α level of 0.05 and a 95% confidence interval was used. The use of the interventional training method significantly reduced the care burden among the parents ($P=0.039$), which was associated with the rejection of the null hypothesis. Nevertheless, this difference had no effect

on the parents' anxiety ($P=0.217$). Hence, in this respect, the null hypothesis was confirmed. Our null hypothesis regarding the difference between the level of anxiety after and before the intervention was confirmed, and the level of care burden was rejected. The results also showed that the level of care burden in the intervention group after the intervention was significantly reduced compared to the pre-intervention phase.

DISCUSSION

The present study aimed to investigate the effect of family-centered care on the burden of care and anxiety in the parents of children undergoing heart transplantation. The results showed that the use of the interventional-educational method significantly alleviated the care burden of the parents ($P=0.039$), which was associated with the rejection of the null hypothesis. Still, this difference failed to affect the patients' anxiety ($P=0.217$). Accordingly, in this respect, the null hypothesis was confirmed. Our null hypothesis with respect to the difference between the level of anxiety after and before the intervention was confirmed, and the level of care burden was rejected. The results also showed that the level of care burden in the intervention group after the intervention fell significantly compared with the pre-intervention phase, while the other group exhibited no significant difference in this regard.

A study of anxiety in the parents of children undergoing cardiac catheterization surveyed 113 subjects and reported that anxiety was high.¹³ In the present study, the parents who participated in the training sessions had better outcomes in terms of anxiety and care burden. Thus, it seems that the educational participation of families is one of the measures that can provide a good basis for improving the clinical condition of patients. Agrawal et al²⁸ reported that their

preliminary evidence suggested that patient-centered and family-centered care was associated with improvements in the self-efficacy of young patients with illnesses. However, there were very few identified studies, and the cases identified were primarily in the field of mental health, which requires further research.²⁹ Other studies have also recommended care and support for patients' families.^{30,31}

A previous study recommended that parents use specific resources to help them navigate into the healthcare system, thereby providing better support to their children. That investigation also recommended that pediatric cardiologists and their staff draw upon patient and family-centered care principles to furnish more effective care for their children.³² In another descriptive study, a new clinical program that integrated psychological services into a pediatric cardiovascular clinic was evaluated. Patients with CHD (79 patients) were referred for psychological services by their pediatric cardiologist. Parents completed a Checklist of Child Behavior and Child Quality at the Main Inventory Scales (PedsQL Parent Report). Reasons for referral included emotional problems (29%), attention problems (25%), learning difficulties (22%), behavioral problems (16%), and developmental delay (8%). Parents and educators reported higher rates of behavioral problems and lower quality of life than the general population. Psychological evaluation suggested that the participation of a psychologist in a pediatric cardiology clinic might be beneficial for children with CHD in optimizing their mental functioning.³³ In a study on parents, the perception of the disease, the severity of the disease, and the quality of life in school-age children aged 5 to 12 years with CHD, children's general quality of life scale 4.0 core scale (PedsQL) (total, physical health, and psychosocial summary health scores) and the Heart-

Specific HRQOL Scale (PedsQL 3.0) scores were compared among CHD severity categories by analysis of variance. Based on the results of that study, interventions should focus on targeting mental health in older children with CHD and physical health in children with CHD. This information is useful in providing practical advice in caring for the parents of children with CHD while being aware of relevant policies.³⁴ In another study on families and heart transplantation in the final stages of heart disease, it was found that family care in the heart transplantation process was vitally important. With the aid of a constructivist-based theory approach, study data were collected from 12 health professionals and 15 families. One of the members was a heart transplant recipient at the third stage of the heart transplant process. Families reported that access to system-level support for family care varied. The results showed that family care was an important factor in the successful recovery of heart transplantation. Effective family care can be ensured through the provision of support for family members at all stages of the heart transplantation process.³⁵ The results of that study are consistent with the results of the present study. In addition, in a study on the effects of the family-centered care model on blood pressure and the dimensions of empowerment in the elderly with hypertension, the results showed that the implementation of a family-centered care model was associated with control and improvement of blood pressure.³⁶ In other studies, education has had a positive effect on parents.³⁷

CONCLUSIONS

The results of the present study showed that after training, the level of anxiety and care burden in the intervention group improved compared with the control group. Information support of patients' families

will help them to better adapt in the face of stressful situations. Educating patients and their families can bolster their information and ameliorate their anxiety.

Acknowledgments

We express our sincere thanks to all the parents and colleagues who helped us with this research.

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