

Impact of Tele-nursing on Adherence to Treatment Regimen and Quality of Life in Pediatric Patients Undergoing Heart Transplantation Surgery

Abstract

Aims: Heart transplantation brings about a shift in lifestyle and quality of life for children and adolescents post-surgery. These patients must adhere closely to their treatment regimen to maintain graft viability and better adaptation. Enhancing the quality of life in pediatric heart transplant recipients is among the crucial responsibilities of nurses. This study aimed to investigate the impact of a tele-nursing supportive educational program on adherence to treatment and quality of life in children aged 12-18 years.

Instruments & Methods: This study was a quasi-experimental single-group design without control group. This study investigated the effectiveness of interactive and supportive education programs on the quality of life and medication adherence of 41 pediatric patients referred to a specialized hospital for heart transplantation in Tehran. Participants were selected through census sampling and received education through communication software such as WhatsApp, Skype, and Telegram, which were chosen by the patients and their parents. The program lasted for eight weeks, and data were collected using a socio-demographic questionnaire, the Pediatric Quality of Life Inventory for Cardiac Problems, and the Modanloo Medication Adherence Scale. The results of the pre-test and post-test were analyzed using SPSS version 16.

Findings: Results showed a significant improvement in the mean score of quality of life and its dimensions ($p=0.001$) as well as the medication adherence score and its dimensions ($p=0.001$) following the implementation and follow-up of the intervention program.

Conclusion: The intervention program had a positive impact on the quality of life and medication adherence of the participants. Tele-nursing interventions can be an effective and accessible method to enhance treatment adherence and improve the quality of life for pediatric heart transplant recipients.

Keywords: Treatment adherence, heart transplantation, children, tele-nursing, quality of life.

Introduction

Heart transplantation is a critical surgical intervention for patients with medically refractory heart failure and life-threatening cardiac conditions, with approximately 3,500 procedures performed annually worldwide (1, 2). The survival rate post-transplant has notably improved, with pediatric patients constituting around 14 percent of these surgeries (3, 4). This procedure is essential for children suffering from congenital diseases, valvular heart disorders, and cardiomyopathies that have not responded to conventional treatments (5). However, heart transplantation significantly impacts the lives of these children and their families, making it vital to maximize survival and quality of life (6).

Post-transplant, patients are prescribed immunosuppressive regimens, including Calcineurin inhibitors, Azathioprine, Everolimus, and corticosteroids, to mitigate rejection risks (7). Research highlights various cognitive and developmental challenges faced by children and adolescents following transplantation, often linked to factors like decreased cerebral perfusion (8). A study in Iran reported a 50% five-year survival rate among heart transplant recipients, with some patients surviving 25 years post-surgery (9). Evidence suggests that treatment adherence is directly related to survival rates, indicating that compliance can enhance outcomes (1, 3, 4).

To improve survival rates, healthcare teams focus on enhancing quality of life and preventing adverse physical, psychological, and social effects. Treatment adherence is crucial for both quality of life and survival among pediatric heart transplant recipients (3, 4). The quality of life in patients with heart transplants is affected by their adherence to the treatment regimen. Chronic illnesses, including heart transplantation in children, have consequences across physical, psychological, social, educational, and occupational dimensions. Despite increased survival rates, these children may not have a satisfactory quality of life (4). Non-adherence can lead to severe consequences, including increased healthcare costs, frequent hospitalizations, transplant rejection, and even mortality (10).

Research indicates that treatment adherence significantly influences the survival rate of pediatric heart transplant recipients, an area requiring further investigation. Treatment adherence also reciprocally affects these children's quality of life, underscoring the need for effective follow-up

strategies (4, 11). Emphasis is placed on repeated visits, enhanced capacity, social support, and continuous education by the childcare team (12). Innovative approaches, such as communication technologies, are increasingly empowering individuals with chronic health conditions. The rise of tele-nursing, particularly in Iran, shows promise, with studies indicating improved self-care through mobile communication and social media (13-15).

Limited studies exist regarding the use of tele nursing in the pediatric and adolescent populations. Most existing studies have predominantly focused on a narrow range of conditions, primarily common acute illnesses (e.g., respiratory infections, minor injuries) or chronic conditions like asthma. Research in this domain largely relies on cross-sectional data, focusing on immediate outcomes rather than long-term efficacy and impact. Populations such as children with severe chronic illnesses may need tailored tele-nursing approaches (16, 17). Current research does not adequately address how tele-nursing services can be adapted to meet these unique requirements. Understanding how tele-nursing can meet the needs of vulnerable populations is essential for promoting health equity and ensuring that all children receive appropriate healthcare services.

Enhancing quality of life and improving treatment adherence in pediatric heart transplant recipients are key nursing responsibilities. Given the available knowledge, researchers have concluded that there has been no study conducted in Iran regarding the impact of tele nursing on pediatric heart transplant recipients. Therefore, this study aimed to investigate the effect of a supportive teleeducational program on treatment adherence and quality of life in children aged 12-18 years.

Methods and Materials

Design

This quasi-experimental single-group study was conducted on children undergoing heart transplantation surgery from October 1st to December 1st, 2022, in Tehran, Iran.

Setting

This study was conducted at Shahid Rajaei Heart Hospital. This hospital is the largest specialized and subspecialized center for heart surgeries in Tehran, where patients in need of heart transplantation surgery are referred. In the present study, 41 children aged between 12 and 18 years, who had undergone heart transplantation surgery at Shahid Rajaei Heart Hospital in Tehran, were selected through a convenient and comprehensive sampling method.

Participants

The study included all children aged 12-18 years who had undergone heart transplantation surgery in the past 5 years and whose health status was being monitored at Shahid Rajaei Hospital during the study period. To be included, participants had to meet several criteria, including the willingness of both parents and children to participate, the ability to speak Persian, the absence of mental disorders and sensory impairments, and access to a mobile phone supporting communication programs. Participants underwent heart transplantation surgery between 6 months and 5 years before the study. Those who were re-hospitalized for any reason during the intervention or experienced a stressful event, such as the death of their parents, were excluded.

First, a list of patients was prepared. Out of 50 patients on the list, 41 met the inclusion criteria. Since the sampling of this research was carried out in an educational and treatment metropolitan hospital in Tehran, Iran, and considering the possibility of dropping samples, the participants were selected by census sampling.

Procedures and Interventions

The Ethics Committee of Shahid Beheshti University of Medical Sciences has approved the protocol for this study. After obtaining the ethics code IR.SBMU.PHARMACY.REC.1399.178 and necessary permits, the researcher, in coordination with the hospital's archive department, prepared a list of eligible children for participation in the study, including their names and contact information. The parents of the children were contacted by phone to explain the purpose, objectives, and implementation of the study. After obtaining consent from both the parents and their children, they were requested to attend an introductory session, sign a written consent form, and receive a general guide on accessing teleeducation and nursing care at the hospital. During the face-to-face session, the plan's objectives and implementation method were reviewed, and written consent was obtained from both the legal guardian and the child. It was also made clear that they could withdraw from the study at any time if they wished.

The educational and supportive content was divided into two parts:

The content was balanced and bias-free, and causal connections between statements were established.

Part one: Included a common section where participants received an audio-visual file and text-based instructional material. The language used was clear, concise, and objective, with a formal register and precise word choice. The text adhered to conventional structure and formatting features, with consistent citation and footnote style. The text was grammatically correct and free from spelling and punctuation errors. No changes in content were made beyond improving the text according to the desired characteristics. This program covered medication regimen, dietary regimen, physical activity, social participation and interaction, mental health, and motivation. This educational content was developed, validated, and confirmed through a review of relevant texts and feedback from professors at the Faculty of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences, the Educational Research and Treatment Center for Cardiovascular Diseases at Shahid Rajaei Heart Hospital, and the research team.

Part two: As the children had undergone transplantation surgeries at different times, ranging from six months to five years ago, they had varying informational and psychological needs. Therefore, the researcher prepared a checklist to identify the unique needs of each child and their family. The checklist was developed by reviewing texts, using questionnaires, obtaining feedback from relevant professors, and surveying and conducting short interviews with several families whose children underwent heart transplantation surgery.

The parents chose communication software, including WhatsApp, Skype, and Telegram, for interacting with families and providing educational content. Telephone calls were made every other day for eight weeks to follow up and answer questions from both parents and children. All children actively participated in the program throughout the intervention. Information was provided in various formats, including audio files, visual materials, and videos, as well as through telephone communication. The study involved a WhatsApp group consisting of all participating children. A daily topic for discussion was raised, allowing the children to interact and discuss self-care management. The participants completed study questionnaires online twice: once before the start of the intervention and again at the end of the eight-week intervention period.

Outcome Measure

The study aimed to evaluate the level of adherence to the treatment regimen and quality of life in adolescents who underwent heart transplantation.

Data collection tools included:

1. Demographic questionnaire for children and parents, which covered gender, age, number of siblings, birth order, presence of other chronic diseases, frequency of hospitalizations, time of transplantation, parents' age and education, place of residence, and socioeconomic status.
2. The Pediatric Quality of Life Inventory™ 3.0 Cardiac Module16 (PedsQL™ 3.0 Cardiac Module): The Pediatric Quality of Life Inventory is a specific tool used to measure health-related quality of life in children and adolescents with heart disease. The language used is clear, concise, and objective, with technical terms explained when first used. No changes in content have been made. It consists of 27 items across six dimensions: heart problems (seven items), treatment (five items), perceived physical appearance (three items), treatment anxiety (four items), cognitive problems (five items), and communication (three items). The scoring system for quality of life is based on a 5-point Likert scale (0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = almost always). The items are reverse-scored and linearly transformed to a scale of 0 to 100 (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), with higher scores indicating worse quality of life. The total score is calculated as the sum of all items. This tool was translated and validated in the Persian language by Noori et al. The internal consistency was confirmed using Cronbach's alpha, which was reported as 0.87 (18). In the current study, Cronbach's alpha was recalculated using all the samples and found to be 0.89.
3. Modanloo et al. (2013) medication adherence questionnaire for chronic patients: Modanloo et al. (2013) designed and validated the medication adherence questionnaire for chronic patients. The questionnaire was designed to assess medication adherence. The language used is clear, concise, and objective, with technical terms used consistently throughout. The text is free from grammatical errors, spelling mistakes, and punctuation errors. The questionnaire comprises 40 items and subscales, including compliance with treatment (9 items), willingness to participate in treatment (7

items), ability to adapt (7 items), integration of treatment into life (5 items), adherence to treatment (4 items), commitment to treatment (5 items), and management in treatment execution (3 items). The text adheres to conventional academic structure and formatting, with clear section headings and citations. The tool measures compliance with treatment, willingness to participate in treatment, ability to adapt, integration of treatment into life, adherence to treatment, commitment to treatment, and management in treatment execution. Scores range from 0 to 45 for compliance, 0 to 35 for willingness, 0 to 35 for adaptability, 0 to 25 for integration, 0 to 20 for adherence, 0 to 25 for commitment, and 0 to 15 for management. Higher scores indicate better adherence to treatment. The developers confirmed the content validity of this tool. The tool's reliability was reported as 0.875 using the test-retest method (19). In this study, we re-evaluated the tool's reliability using the test-retest method on 10 adolescents who were not part of the sample ($r = 0.88$).

Data analysis

The SPSS version 16 software was used to analyze the data. Descriptive statistics were utilized to present the demographic characteristics and mean scores of quality of life and treatment adherence. The normal distribution of variables was confirmed using the Kolmogorov-Smirnov test. The mean scores of quality of life and treatment adherence were compared at two-time points (before and after intervention) using analysis of variance (ANOVA). The study employed a paired t-test to compare the mean scores of quality of life and treatment adherence before and after the intervention. Additionally, the study used the Pearson correlation coefficient to examine the relationship between demographic variables and treatment adherence or quality of life.

Results

The study participants had a mean age of 12.66 ± 2.29 years, with 51.2% being girls. The majority of participants (26.8%) were in the sixth grade and did not have any other chronic diseases (99.2%). Three fathers had passed away previously. The majority of fathers (58.6%) had less than a diploma degree, while the majority of mothers (41.5%) had a diploma degree. The age range of mothers in the study was between 31 and 54 years, while for fathers it was between 36 and 64 years. In 73.2% of cases, mothers were the primary caregivers. Additional demographic and clinical information can be found in Table 1.

The lowest mean was related to post-treatment with a mean of 44.3 ± 78.3 , while the highest mean was related to cognitive problems post-treatment with a mean of 21.4 ± 90.7 . The study found that the mean and standard deviation of quality of life before the intervention were 58.31 ± 15.63 . Following the intervention, the mean and standard deviation of quality of life were 10.65 ± 21.4 . The quality of life questionnaire results showed that the lowest mean score was related to cognitive problems post-treatment, with a mean of 34.1 ± 91.0 , while the highest mean score was related to communication problems post-treatment, with a mean of 31.2 ± 31.2 . A lower score on the questionnaire indicates a higher quality of life. Furthermore, the paired t-test results indicated a significant difference in quality of life and its dimensions after the intervention compared to before the intervention ($p < 0.001$) (Table 2).

Before the intervention, treatment adherence had a mean of 21.172 ± 13.68 . The lowest mean was related to treatment implementation post-treatment with a mean of 29.5 ± 65.2 , and the highest mean was related to adherence to treatment post-treatment with a mean of 40.56 ± 16.4 . After the intervention, treatment adherence had a mean of 82.177 ± 81.6 . The study found that the lowest mean score was associated with treatment implementation post-treatment (90.7 ± 10.4), while the highest mean score was associated with adherence to treatment post-treatment (47.56 ± 67.6). The results of the paired t-test indicated a significant difference in adherence to treatment and its dimensions after the intervention compared to before the intervention ($p < 0.001$) (Table 3).

Table 1. Demographic and clinical characteristics of study participants (N= 41)

Variables	Frequency	Percent
Fifth Grade	8	19/50
Sixth Grade	11	26/80
Seventh grade	10	24/40

Level of education of adolescents	Eighth grade	7	17/10
	9th and 10th grade	5	12/20
Level of education of fathers	High school / Diploma	31	75/60
	College education	10	24/40
Level of education of mothers	High school / Diploma	33	80/50
	College education	8	19/50
Father's' occupation	Professional employee	8	21/05
	Non-professional employee	17	44/75
	Self-employment	10	26/35
	Retired	3	7/85
	housewife	34	82/9
Mother's' occupation	Professional employee	6	14/6
	Retired	1	2/4
	Less than 1 years	7	17/07
Elapsed time since heart transplant	1-3 years	26	63/42
	More than 3 years	8	19/51
	Frequency of hospitalizations during the past year	1-3 times	32
	4-6 times	9	21/95
Chronic illness in parents	Yes	10	24/50
	No	31	75/50
The family' economic status	weak	13	31/7
	Average	24	58/5
	Good	4	9/8

Table 2. Comparison of the average score of quality of life in participants before and after the intervention

Dimensions	Pre-intervention	Post-intervention	Score in the inventory	Paired t-test	p-value
	Mean ± SD*	Mean ± SD			
heart problems	6/95±4/90	2/14± 1/44	0-6	5/871	0/001
treatment	3/78± 3/54	1/56±1/14	0-5	3/850	0/001
perceived physical appearance	3/87± 3/44	1/65± 1/08	0-4	4/008	0/001
treatment anxiety	5/07± 4/98	1/63± 1/15	0-5	4/327	0/001
cognitive problems	7/90± 4/21	1/34± 0/91	0-3	10/203	0/001
communication	4± 3/61	2/31±2/31	0-5	3/101	0/001
Total	31/58± 15/63	10/65± 4/21	0-28	8.620	0/001

* Standard Deviation

Table 3. Comparison of treatment adherence in participants before and after intervention

Dimensions	Pre-intervention Mean ± SD	Post-intervention Mean ± SD	Score in the inventory	Paired test	t-	p-value
Compliance with treatment	40/56±4/16	47/26± 6/67	45-29	9/432		0/001
Willingness to participate in treatment	32/95± 2/48	37/05±4/67	26-35	6/865		0/001
Ability to adapt	30/39± 4/45	33/10± 7/07	11-35	5/234		0/001
Integration of treatment with life	19/56±3/91	24/90±4/87	6-25	8/901		0/001
Adherence to treatment	17/63±2/22	19/56±4/02	12-20	7/643		0/001
Commitment to treatment	11/58±2/71	15/08±3/11	8-20	5/908		0/001
Management in treatment execution	5/29±2/65	7/90±4/10	3-15	7/213		0/001
Total	172/21±13/68	177/82± 6/81	95-195	3/053		0/001

Discussion

The purpose of this study was to investigate the effects of tele nursing care on treatment adherence and quality of life among 12-to 18-year-old children who underwent heart transplant surgery at Shahid Rajaei Hospital in Tehran. The study's findings indicate that an eight-week tele supportive-educational and nursing program improved participants' quality of life across all dimensions and increased adherence to their treatment regimen. This research is significant due to its innovative approach and the accessibility it provides to caregiving information for children and their families. Furthermore, the study was conducted during the COVID-19 pandemic, which presented challenging conditions and the risk of disease spread. The intervention was delivered continuously.

Although there have been limited studies on the impact of tele nursing on the quality of life and treatment adherence of pediatric heart transplant recipients, this care program has been shown to improve patients' quality of life and enhance their cardiac health (20). Compared to other surgical procedures, heart transplant surgery patients experience higher levels of stress and are required to adhere to more complex treatment regimens. This significantly affects their quality of life and treatment adherence, which may decrease.

Scientific evidence indicates that promptly educating patients through tablets or smartphones can improve their knowledge levels, treatment adherence, satisfaction, and, most importantly, clinical outcomes. This, in turn, can positively impact the economy of the healthcare system. This effect has been observed in interventions lasting less than one month (21). In a study, Seraj et al. investigated the impact of tele-nursing on treatment adherence in adolescents undergoing heart surgery. The experimental group received tele-nursing services via the WhatsApp messaging platform for one month. The results showed an improvement in treatment adherence across all dimensions following tele-nursing (20), which is consistent with the findings of the present study. Therefore, it is recommended to create a conducive environment to increase the utilization of this approach through public awareness campaigns and the empowerment of nursing staff. However, there are differences between this study and the present research: Seraj et al.'s study considered all types of heart surgeries, whereas the present study focused solely on heart transplant surgery. Although the ages of the participants in both studies were similar, the type of surgery and its associated care can significantly impact the quality of life. Therefore, the results of both studies emphasize that tele-nursing care can be effective in improving treatment adherence in children and adolescents undergoing heart surgery.

A study conducted by Kelly et al. aimed to improve access to care and medication adherence among adolescent transplant recipients. This study is similar to the present study in terms of research community and intervention. The study employed a virtual tele-intervention via video conferencing,

which the participants found to be both acceptable and engaging. Consequently, medication adherence increased (22). Meyer et al. (2021) implemented a 24-week web-based physical activity intervention for children with congenital heart disease. The study found that children responded well to virtual instructions and tele treatment (23). Tele nursing and the use of electronic devices and virtual spaces are particularly appealing to children and adolescents. This has led to improved satisfaction with such interventions and consequently enhanced treatment adherence. Therefore, leveraging this excellent opportunity, tailored to disease and surgical care, tele education, and care can be implemented effectively.

Moreover, the efficacy of tele nursing in enhancing treatment adherence has been demonstrated in other chronic conditions, including epilepsy (24). It is recommended to conduct additional studies to compare the effectiveness of various tele nursing care methods, such as virtual education, web-based interventions, and telephone follow-ups, given their diversity and differences.

Limited research has been conducted on the effects of tele nursing interventions on quality-of-life indicators in pediatric and adolescent heart transplant recipients. A pilot study has recently implemented a virtual cardiac readiness program for patients undergoing heart transplant surgery to determine its impact on physical readiness and quality of life. In this study, adolescents aged 10 to 20 underwent a 16-week intervention with biweekly exercise sessions lasting 30 minutes each, led by a trained physiologist on a virtual platform. The successful implementation of virtual cardiac readiness was associated with excellent adherence and improvements in physical readiness and quality of life indicators. Specifically, improvements were observed in fatigue level and sleep quality (25). This study has shown that physical exercises can be conducted virtually, making them practical during critical times such as the COVID-19 pandemic. Although the overall quality of life scores improved in these patients, a more detailed analysis revealed an increase in the anxiety component, which is a crucial dimension of quality of life. This finding contradicts the present study's findings. Cardiac patients often experience increased anxiety as their first psychological response, which can significantly impact their quality of life. This finding may be attributed to the stressful period of COVID-19, which has exacerbated the situation. It is undeniable that COVID-19 has had adverse effects on the mental health and well-being of chronic and cardiac patients (26).

Another study has demonstrated that participation in a physical activity program can enhance the quality of life of children with heart disease and heart surgery, particularly those with low baseline quality of life (27). Nurses can integrate physical activities and exercise programs into tele education and care programs to improve patients' health outcomes.

However, it is important not to overlook the significance of following up on treatment progress and identifying patients' needs after discharge (28), particularly for children undergoing heart surgery, where care is often family-centered. In these cases, the importance of tele nursing is evident. A study was conducted to evaluate the impact of a discharge and follow-up program based on a nursing process model in 5 sessions on the quality of life of children undergoing heart surgery. The program was designed to determine educational needs, provide emotional support, and follow up on care. The results showed that following the program based on the needs of parents and children and tele follow-up significantly enhanced the quality of life of these patients (29). These results are consistent with the findings of the current study. However, there are differences between the two studies. In the present study, the target population consisted of pre-transplant children, whereas in the mentioned study, school-aged children with congenital heart diseases undergoing surgery were included. Nevertheless, both studies demonstrated that educational and counseling interventions post-discharge could improve children's quality of life. Furthermore, the study was conducted amidst the COVID-19 pandemic, which has had a significant impact on the quality of life of children under these circumstances.

In contrast to the findings of the present study and other studies, Weigmann-Faßbender and colleagues' study, which aimed to investigate the effect of a video game program on the quality of life and fitness of children receiving kidney transplants, showed no impact on the quality of life (30). Merely focusing on children's interests without increasing their awareness and knowledge about the disease cannot generally improve their quality of life. Quality of life is a multidimensional concept, and improving one aspect of it with entertainment alone may not be sufficient. Therefore, it is necessary to increase children's awareness and knowledge about the disease and its surrounding conditions. One difference between the present study and the referenced study is the type of intervention and the research population. It is important to note that kidney transplant recipients

have different conditions compared to heart transplant recipients, and their quality of life may be influenced by different factors.

This study demonstrates that tele-nursing significantly improves treatment adherence and quality of life among pediatric heart transplant recipients. These findings align with previous research indicating that telehealth interventions can enhance patient outcomes (17, 21). The improvement in treatment adherence from 172/21±13/68 to 177/82±6/81 post-intervention suggests that remote support may mitigate the barriers to compliance often faced by pediatric patients.

Conclusion

This study provides compelling evidence that tele-nursing can positively impact treatment adherence and quality of life for pediatric heart transplant patients. These findings support the integration of telehealth solutions into routine care practices for this vulnerable population. Further studies are warranted to explore long-term outcomes and optimize tele-nursing strategies tailored to individual patient needs.

Limitations and Future Research

Despite these positive outcomes, several limitations must be acknowledged. The study's quasi-experimental design restricts causal inferences due to potential confounding variables that were not controlled for in the analysis. Additionally, while our sample size was adequate for preliminary findings, larger studies are necessary to generalize these results across diverse pediatric populations. Future research should explore the long-term impacts of tele-nursing interventions on both adherence and quality of life and investigate potential barriers to implementation in various healthcare settings.

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Ethical Permission

This article was a part of the master's thesis in nursing approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences, Tehran, Iran under the ethics code IR.SBMU.PHARMACY.REC.1399.178. All methods were performed in accordance with the declaration of Helsinki. After explaining the research objectives, we obtained written informed consent from all participants and informed them about the confidentiality of the data. For participants under age 16, it was obtained from their parent or legal guardian. Informed consent was obtained from their next of kin/legally authorized representative for illiterate participants.

Authors' contributions

SMHM, MV, MB, and MNou designed the study and reviewed the study materials. MV submitted the ethics approval, while MM and SMHM collected the data. MNou and MNa supervised the implementation of the study. Finally, all authors reviewed and edited the draft and approved the final manuscript.

Data Availability

The datasets generated and/or analysed during the current study are not publicly available due to confidentiality concerns but are available from the corresponding author on reasonable request.

Conflicts of Interest

The authors declare no competing interests.

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