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Case Report

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Respiratory Physiotherapy in a Pediatric Patient with Congenital Dilated Cardiomyopathy Supported by a Ventricular Assist Device: A Case Report

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Abstract

Background: Ventricular assist devices (VADs) have become an established therapeutic option for children with advanced heart failure. However, evidence regarding respiratory physiotherapy in pediatric VAD recipients remains limited.

Objective: To describe the clinical course and functional outcomes of a specialized respiratory physiotherapy program in a pediatric patient with congenital dilated cardiomyopathy supported by a VAD.

Case Presentation: A 14-year-old girl with MYH7-related congenital dilated cardiomyopathy underwent Berlin Heart biventricular assist device implantation. A structured rehabilitation program included airway clearance techniques, assisted breathing exercises, inspiratory muscle training, early mobilization, gait re-education, and progressive strengthening.

Results: Assessments were performed at baseline, discharge, 6 months, and 12 months. Pain decreased from VAS 6 to 0, muscle strength improved from MRC grade 3 to 4, dyspnea and perceived exertion decreased, and quality-of-life scores improved across all SF-36 domains. Chest radiography demonstrated resolution of postoperative pulmonary abnormalities. No rehabilitation-related adverse events were observed.

Conclusions: Early respiratory physiotherapy appears feasible, safe, and potentially beneficial in pediatric patients receiving VAD support. Further multicenter studies are required to establish evidence-based rehabilitation guidelines.

Keywords: Ventricular assist device (VAD); respiratory physiotherapy; pediatric patient; quality of life (QoL).

Introduction

This case report, conducted according to the CARE guidelines [1], describes the medical history, clinical history, surgical intervention, and rehabilitation process of a 14-year-old patient who underwent VAD implantation for congenital dilated cardiomyopathy.

The number of pediatric patients with advanced heart failure, whose etiology includes conditions such as acute myocarditis, cardiomyopathy, and various forms of congenital heart disease, is steadily increasing, and until a few decades ago, the only therapeutic option was heart transplantation [2].

In many countries, however, children on the waiting list for this procedure still tend to have longer waiting times than adults, and a significant proportion of patients die due to disease worsening while waiting for a compatible heart donor: the average waiting period for a pediatric donor is estimated to be 119 days, with a waiting list mortality rate of 23% [3].

From this perspective, mechanical extracorporeal cardiopulmonary support devices represent the best management strategy for terminally ill patients awaiting transplantation. Although implantable devices have always been widely available for adults, adequate support systems have only recently been approved for pediatric patients.

In 1991, however, one of the first pediatric extracorporeal cardiac assist devices, the EXCOR Pediatric Berlin Heart VAD (Ventricular Assist Device), was developed and put into clinical practice in collaboration with the Deutsches Herzzentrum Hospital (Berlin, Germany), the subject of this study. (Figure 1, Figure 2).

Figure 1 VAD

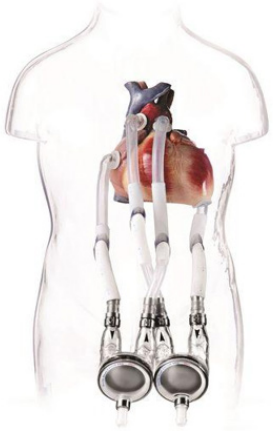


Figure 2 VAD

Initial analyses of this device, which received marketing approval in Europe in 1996, demonstrated that it could provide stable circulatory support for at least 421 days even in children weighing as little as 3 kg, and that patients could be extubated from mechanical ventilation, transitioned to parenteral/enteral nutrition, and become ambulatory. Thus, the device not only kept children alive long enough to receive a transplant, but also improved their quality of life while waiting, making them better candidates for the procedure itself [3].

The EXCOR Pediatric Berlin Heart ventricular assist device (VAD) is implanted using standardized surgical techniques, with the aid of extracorporeal circulation (ECC), which ensures blood circulation and oxygenation during the procedure.

After the cannulas are inserted through the chest wall, they are connected to the blood pump. The VAD monitoring team monitors the pump's flow rate and pressure via the fixed drive unit, intervening in the event of malfunctions. Once the procedure is complete, the patient is gradually weaned from ECC, and the ventricular assist device takes over complete cardiac flow management, ensuring systemic hemodynamic stability [3].

The rehabilitation process for a patient undergoing this type of surgery, who will likely experience symptoms such as dyspnea, muscle fatigue, and cardiac rhythm changes, should begin immediately postoperatively. This is because, immediately after VAD implantation, pulmonary capillary and ventricular pressures decrease dramatically, and systemic arterial pressure improves due to increased cardiac index and blood flow. Within the first 2 months, oxygenation capacity, quality of life, and walking tolerance improve, and over 80% of patients return to a New York Heart Association Classification I or II [4].

Physiotherapy focuses primarily on the respiratory system, including clearing the airways, positioning the patient for drainage, and maintaining respiratory muscle function. This is followed by musculoskeletal treatment, which assesses the patient's strength and level of independence in basic functional activities, such as bed mobility, transfers, and walking, with the aim of regaining lost independence.

Although specific guidelines for the rehabilitation management of adult patients with VAD already exist, specific pediatric physiotherapy programs have not yet been published in the literature.

The rehabilitation protocol adopted by the Respiratory Physiotherapy Unit of the hospital that treated the patient described in this case report includes autogenic drainage of secretions, secretion suctioning, volumetric stimulation in cooperative patients, assisted respiration, respiratory muscle training, gait rehabilitation, and muscle strength training.

This study will therefore describe in detail the medical history, rehabilitation intervention, and clinical course of the patient, treated between May 2024 and September 2025.

Materials and Methods

The patient in this study is a 14-year-old girl, weighing 38.3 kg and 153 cm tall.

She was born full-term with eutocic birth (full-term at 41 weeks) and exhibited normal physical and mental development. She grew up in Italy and is currently a first-year high school student.

On physical examination, she appears active, cooperative, and feeds without difficulty.

She exhibits no symptoms at rest, but upon exertion, she reports moderate breathing difficulties and mild fatigue. Growth is fair, particularly in height rather than weight.

The patient's medical history includes a history of dilated cardiomyopathy, which began with heart failure at 6 months of age. She has been placed on the waiting list for an orthotopic heart transplant since January 24, 2012, following genetic testing that revealed a de novo heterozygous mutation in MYH7, considered pathogenic.

The patient came to our attention at age 13 following implantation of a ventricular assist device (VAD) and subsequent orthotopic heart transplant.

The patient's medical history includes a family history of sudden infant death, difficulty breathing, primarily during exertion, and a feeling of chest pressure, especially at night, even during sleep.

The patient's comorbidities include bronchial asthma and, more recently, thrombosis of the left internal jugular vein up to the jugulosubclavian confluence.

Figure 3 shows the clinical and therapeutic path of the patient who was the subject of this study:

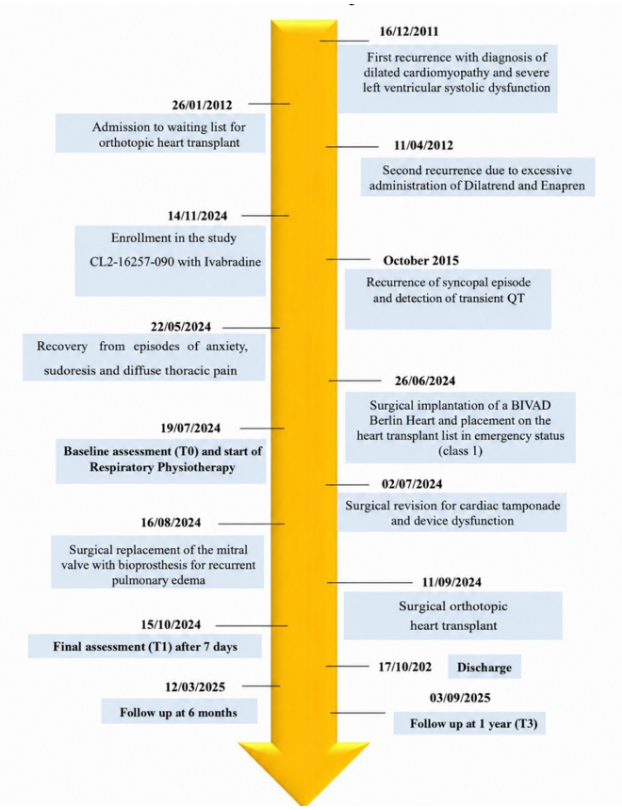


Figure 3: Clinical and therapeutic pathway

Before physiotherapy treatment, the patient underwent the following diagnostic tests:

- Chest x-ray in frontal projection in clinostatism: Diffuse accentuation of the peribronchovascular interstitium with more evident findings in the mid-basal area bilaterally; limited shaded opacity on a dysventilatory basis in the left retrocardiac basal area; no pleural effusion; cardiac image with prominence of the inferior arches.

-Heart TC: regular patency of the venous and arterial axes of the neck, of symmetrical caliber; atriomegaly, with severe dilation of the left atrium and mitral annulus; globose ventricles, particularly the left, with mid-apical hypertrabeculation in known condition of non-compact myocardium; in the pulmonary area, scattered, fine septal thickenings are appreciated bilaterally, probably with mild interstitial involvement, neither pleural nor pericardial; the main airways are patent, with moderate thickening of the walls of the bronchial branches.

-**Transthoracic Echocardiogram:** Severely dilated left ventricle with mild systolic dysfunction, ejection fraction (EF) of 52%, normally contractile right ventricle; severe tricuspid regurgitation, with estimated right ventricular pressure approximately 55-60 mmHg + DBP

-**ECG Holter:** reduced HR variability with mean HR 82 bpm, NT-proBNP blood tests approximately 400 pg/ml slightly decreasing

-**Stress test (January 2024):** duration of effort 9.3 min, 10.6 METs, good blood pressure increase, HR increase limited by therapy (max 130 bpm equal to 62% of HRMT), sporadic ESVB and late VEB isolated during the exam; no alterations of RV due to effort

-**Global spirometry with diffusion:** FVC L 2,37 (64% pr), FEV 1 L 1,84 (56% pr), FEV1/FVC% 87, FEF25-75% L/s 1,62 42%

The patient underwent surgical implantation of a ventricular assist device (BIVAD Berlin Heart) on June 26, 2024, and was subsequently transferred to the Cardiac Intensive Care Unit (CCU) as per standard practice for monitoring of her general clinical condition and proper device placement.

Immediate post-surgical radiography revealed mild thickening of the peribronchovascular interstitium and a small amount of bilateral pleural effusion.

The post-operative course included surgical revision for cardiac tamponade and device dysfunction on July 2, 2024, with progressive improvement in the patient's general clinical condition. She was subsequently transferred to the Cardiology department for stabilization of her vital signs.

A respiratory physiotherapy program was prescribed with the primary goal of preventing postoperative complications (such as infections, atelectasis, and accumulation of secretions), improving airway patency, prespiratory mechanics, and respiratory muscle strength.

Physiotherapy Evaluation:

The patient underwent an initial Respiratory Physiotherapy evaluation (T0) on 07/19/2024 using the following outcome measures:

-Visual analog scale (VAS) [6]
-Range of motion (ROM):
-Short form health survey (SF-36) [7]
- Dyspnea Rating Scale (BORG-M) [8]
- Rate of Perceived Exertion Scale (RPE) [9]
- Chest x-ray
- Vital parameters

Postoperative physical examination revealed right convex scoliosis, normal chest size, and moderate functional impairment.

The patient reported moderate chest pain (VAS 6) with a resulting sensation of "pressure" on the chest. A weakness of the left external popliteal sciatic muscle (MRC 3) was also noted; the ROM of the AASS was limited.

The patient was moderately eupneic with a respiratory rate (RR) of 16, heart rate (HR) of 78 bpm, oxygen saturation (SpO2) of 99%, and blood pressure (BP) of 88/69 mmHg; bronchial secretions were present, likely due to the surgical procedure; chest hypoexpansion, particularly in the left retrocardiac basal region; and no pleural effusion.

The SF-36 self-assessment questionnaire obtained the following score:

- Physical Functioning: 50
- Physical Health: 0
- Mental Health: 33
- Energy/Fatigue: 65
- Emotional Well-Being: 72
- Social Functioning: 50
- Pain: 35
- General Health: 5

An evaluation was performed at the end of the 7 rehabilitation sessions (T1), with subsequent follow-ups at 6 months (T2) and 1 year (T3).

The physiotherapy intervention designed for the patient in this study included:

- Bronchial clearing techniques:

1 Autogenous drainage of secretions: initial phase of mucus separation, intermediate phase of secretion collection, final phase of removal; the patient is asked (in a position that facilitates breathing, therefore sitting or supine) to first slowly inhale, then hold his breath for 3-4 seconds to evenly fill the entire lung, and finally to forcefully exhale to evacuate the secretions by coughing.

2 Assisted manual drainage (postural maneuvers with clapping and vibrations): With the patient in the lateral decubitus position, cupping is applied to the chest during exhalation, causing an oscillatory motion within the airways to dislodge secretions. Vibratory pressure is then applied in a caudal-cranial direction to move them upward. Once the lungs are almost completely emptied, the patient is asked to cough. (Figure 4)

It is normal for the secretions to appear to be increasing during the first sessions, as the aforementioned techniques will dislodge the stagnant secretions lower down.

Figure 4: Drainage of secretions.

3. Assisted cough stimulation: during the expiratory phase, coughing causes the bronchial walls to vibrate, resulting in the loosening of secretions. Therefore, the therapist places their hands on the patient's chest to apply sufficient pressure to stimulate an effective cough.

- Early mobilization: performed in the immediate post-operative period with the aim of reducing the effects of prolonged immobilization, such as pulmonary stasis, formation of pressure ulcers, muscle wasting or orthostatic hypotension.

This included:

1. Patient education on the various precautions to be taken for sternotomy, including avoiding asymmetric upper limb movements (AASS), not moving the arm backward beyond the midline of the body, and not sleeping in the lateral decubitus position for approximately 45 days.

2. Passive and subsequently active-assisted mobilization (AASS and AAII).

3. Postural transitions: already in the acute phase of rehabilitation, the patient was able to first achieve a sitting position at the edge of the bed and subsequently also a standing position.

4. Recovery of ambulation: with the support of the physiotherapy team, especially in managing and transporting the device, the patient was able to ambulate within her room.

- Using of the volumetric incentive Coach: A medical device used to increase lung expansion and strengthen respiratory muscles, used after thoracic surgery or in cases of chronic cardiorespiratory diseases (Figure 5); it consists of a handle, a mouthpiece where the patient places their lips, and a graduated volume indicator (plunger) as visual feedback to monitor the amount of air inhaled.

A forced exhalation is first required, after which the patient must slowly inhale through the mouthpiece by raising the plunger, hold their breath for a few seconds, and then exhale through pursed lips. [2]

The patient performed 5 cycles of 10 repetitions each for each session, producing deep breaths with an open glottis.

Figure 5: Volumetric Incentive Coach.

The entire rehabilitation process was carried out by monitoring vital signs before, after and during treatment, the correct functioning of the ventricular assist device (VAD) and any worsening of clinical symptoms reported by the patient herself.

Results

ROM, MRC, VAS

At the end of physiotherapy treatment (T1), no joint limitations of the AASS were observed in all spatial planes, with chest dimensions unchanged compared to T0 and an improvement in functional impotence.

The patient maintained a mild deficit in strength of the external popliteal sciatic muscle (MRC 3) and reported a reduction in chest pain (VAS 4).

At the 6-month follow-up (T2), an improvement in strength of the SPE muscle (MRC 4) and a complete recovery of ROM were observed.

One year after surgery, at the follow-up on 03/09/2025 (T3), the patient reported that no changes of physiotherapy significance were observed, other than a complete reduction in pain.

Regarding the BORG-M and RPE scales, comparing the results obtained at the last 1-year follow-up (T3), clear improvements are visible.

The results are shown in Figure 6.

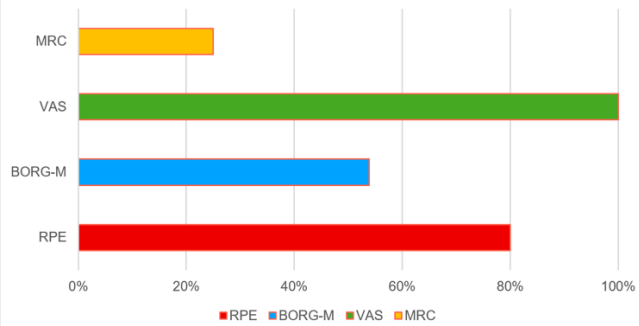


Figure 6: Improvement in RPE, BORG-M, VAS, and MRC.

3.3 SF-36

The administration of this questionnaire proved particularly effective for monitoring the patient's physical, mental, and social health before, during, and after the rehabilitation treatment period.

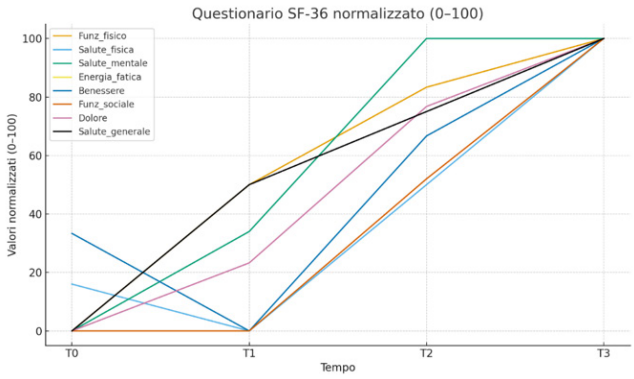
It can be observed that from T0 to T3, all values increased, indicating a clear improvement in health, particularly with regard to items 2 (physical health), 3 (mental health), 7 (pain), and 8 (general health). However, her level of perceived physical/mental energy remained constant.

The results are shown in Table 3 and in Graph 1:

QUESTIONNAIRE	Physical function	Physical Limitat.	Emotional limitat.	Vitality	Mental health	Social function	Bodily pain	General health
T0	50	0	33	65	72	50	35	5
T1	65	25	67	65	68	50	45	25
T2	75	50	100	65	76	63	68	35
T3	80	75	100	65	80	75	78	45

Table 3: SF-36 Results

Since each subscale of the SF-36 questionnaire is composed of a different number of items, in order to compare the scores obtained it is necessary to normalize the values using the following formula: Normalized score = $\frac{x-\min}{max-\min}$ x 100



Graph 1 Percentage of improvement in SF-36 at 12-month follow-up.

Chest XR

In the period between T0 and T1, a significant improvement in the patient's lung condition was recorded, thanks to the respiratory rehabilitation program she completed. (Figure 6)

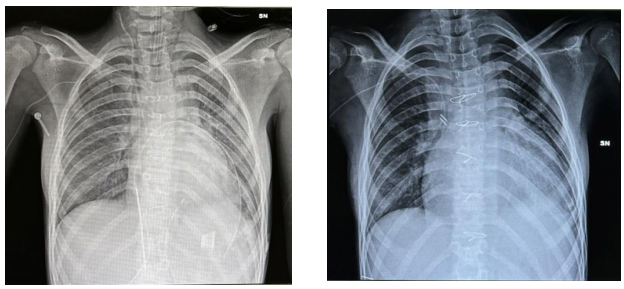


Figure 6: Comparison of T0-T1 chest x-rays.

Observing the first X-ray, taken at the start of rehabilitation treatment (T0), one notices, in addition to the recent implantation of the ventricular assist device, a hyperlucency (darker) area in the upper part of the left lung, due to a small apical pneumothorax with a maximum thickness of 15 mm; thickening of the peribronchovascular interstitium can also be observed.

If, however, one examines the second X-ray, corresponding to the patient's discharge period (T1), one notices the disappearance of the darker area in the apical region of the lung, due to reabsorption of the pneumothorax with consequent re-expansion of the left lung.

On T2 and T3, no significant changes in the radiographic findings are observed compared to the previous ones, confirming a significant improvement in the pulmonary status.

Vital signs

At each physiotherapy session, the patient's vital signs were recorded post-treatment throughout her hospital stay (T0-T1).

A progressive improvement in blood pressure (BP), heart rate (HR), and respiratory rate (RR) was observed. Oxygen saturation (SpO2) remained constant throughout the rehabilitation process, with consistently optimal values and no episodes of desaturation were recorded.

Discussion

This study describes the pulmonary rehabilitation protocol administered to a 14-year-old pediatric patient with VAD who subsequently underwent heart transplantation for congenital dilated cardiomyopathy.

In the absence of specific guidelines in the literature for the management of physiotherapy treatment for pediatric patients with such clinical complexity, the team of physiotherapists who treated the patient adopted the rehabilitation program developed by the Respiratory Physiotherapy Unit of the Bambino Gesù Children's Hospital, already used for patients with cardiorespiratory problems.

Despite the lack of guidelines for pediatric patients, the rehabilitation treatment administered proved effective in improving the clinical, functional, and psychological condition of the patient, as evidenced by all outcome measures examined.

The primary objective of this study was to demonstrate the fundamental role of respiratory physiotherapists in the management of pediatric patients undergoing VAD implantation for terminal cardiac disease. This aim is to reduce the patient's hospitalization, prevent postoperative complications related to prolonged immobilization, improve her quality of life, and fully reintegrate her into society.

In fact, during the postoperative hospital stay and subsequently after discharge, the patient noted not only a progressive improvement in her physical condition but also significant psychological and social benefits: during the two follow-ups conducted 6 months (T2) and 1 year (T3) after the device implantation, the patient reported having returned to school, having resumed her interpersonal relationships, and expressed a desire to resume sports activities.

These elements demonstrate the positive impact of the rehabilitation process not only on the patient's respiratory and motor function, but also on her overall quality of life.

The literature has shown that initiating an early intensive rehabilitation program in patients undergoing VAD implantation is considered safe and can be undertaken as early as the Intensive Care Unit.

In particular, the work of de Jonge et al. documents that patients who underwent intensive cardiopulmonary rehabilitation following device implantation and subsequent heart transplantation demonstrated improved aerobic capacity and were able to perform normal activities of daily living within 12 weeks of surgery. [10]

Although the cited study did not include pediatric subjects, the results obtained in this case report are very similar to the work of de Jonge et al.: in fact, the patient in this study, approximately 12 weeks after the heart transplant, performed following VAD implantation, was able to independently perform normal activities of daily living, without experiencing any recurrence of symptoms attributable to her disease.

This evidence supports the hypothesis that an intensive and personalized rehabilitation intervention can provide comparable benefits even in the pediatric population, despite the absence of specific guidelines.

Conclusion

This case report describes the rehabilitation journey of a pediatric patient with congenital dilated cardiomyopathy who underwent ventricular assist device implantation followed by heart transplantation. Improvements were observed in pain, muscle strength, dyspnea perception, quality of life, pulmonary status, and overall functional capacity.

Although causal relationships cannot be established from a single case report, the findings suggest that early, structured, and individualized respiratory physiotherapy is both feasible and safe in pediatric VAD recipients. The integration of airway clearance techniques, respiratory muscle training, and progressive mobilization may facilitate postoperative recovery and support reintegration into age-appropriate daily activities.

Further prospective studies and multicenter collaborations are needed to define standardized rehabilitation pathways and strengthen the evidence base for respiratory physiotherapy in children receiving mechanical circulatory support.

Conflict of Interest Statement

The authors have no conflicts of interest to declare

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