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Airway-Centered Nursing Care for Advanced Duchenne Muscular Dystrophy with Tracheostomy Dependence and Moderate Scoliosis: A Case Report

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Case Report

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Abstract

Background: Adolescents with advanced Duchenne muscular dystrophy (DMD) frequently have concurrent respiratory insufficiency, scoliosis, malnutrition, immobility and heavy reliance on family care. After tracheostomy, impaired cough and restricted chest expansion impair secretion clearance, making conventional respiratory nursing inadequate. This case adds practical, integrated nursing strategies for the co-occurrence of severe scoliosis, pressure injury risk and ventilation dependence during the transition from hospital to home mechanical ventilation, a scenario rarely detailed in nursing literature.

Case presentation: A 17-year-old male with a 14-year history of DMD was admitted after sudden cardiac arrest at home. Tracheostomy was performed during intensive care because extubation failed. After transfer to the general nursing unit, he remained ventilator dependent and had bilateral pneumonia, severe malnutrition, moderate scoliosis, limited chest expansion, and stage II pressure injuries over the sacrococcygeal region and both ankles.

Interventions: Nursing care was organized around four linked problems: airway clearance, aspiration risk, pressure injury risk, and preparation for home ventilation. Heated humidification was used to reduce secretion drying. High-frequency chest wall oscillation was followed by tracheal suctioning because suctioning alone could not address deep secretion retention. Feeding, oral care, tube fixation, turning, support-pad placement, and standing-bed training were adjusted according to respiratory tolerance and spinal deformity.

Outcomes: By discharge, the patient was hemodynamically stable and had maintained airway patency without documented ventilator-associated pneumonia or further pressure-related skin deterioration during the reported nursing period. Family caregivers completed bedside training in suctioning, inner cannula care, emergency response to tube blockage, and ventilator equipment checks.

Conclusion: This case shows how standard tracheostomy and ventilation care can be adjusted when scoliosis and muscle weakness change secretion clearance, pressure redistribution, feeding safety, and caregiver training.

Introduction

Duchenne muscular dystrophy is the most common severe childhood-onset muscular dystrophy in males. A recent systematic review estimated a global birth prevalence of 19.8 cases per 100,000 live male births [1]. Improvements in respiratory, cardiac, orthopedic, nutritional, and rehabilitative care have extended survival, but they have also made late-stage care more complex [2-4]. Respiratory muscle weakness is one of the main threats in advanced DMD. Recommended care includes respiratory surveillance, noninvasive ventilation when appropriate, cough assistance, and escalation to invasive ventilation when airway protection or gas exchange cannot be maintained [4-6]. Scoliosis adds a second mechanical problem. It restricts chest wall movement and can make positioning, secretion mobilization, pressure redistribution, and feeding safety harder to manage [3,4].

Many articles describe respiratory management in DMD, but fewer describe how bedside nursing changes when tracheostomy dependence and spinal deformity coexist. This case report was prepared with reference to the CARE guideline framework [12]. It describes the nursing decisions used for a 17-year-old adolescent with DMD, tracheostomy dependence, bilateral pneumonia, malnutrition, pressure injuries, and moderate scoliosis.

Clinical Relevance

This case is clinically relevant because several common late-stage DMD problems occurred together and changed routine nursing care. Suctioning had to be paired with secretion mobilization. Turning had to protect the skin without worsening chest expansion. Feeding had to support nutrition without increasing aspiration risk. Discharge education had to be assessed by caregiver performance rather than by completion of verbal teaching.

Case Presentation

A 17-year-old male with a 14-year history of DMD was admitted to the intensive care unit after sudden cardiac arrest at home. Immediate cardiopulmonary resuscitation was performed by family members, followed by return of spontaneous circulation. He had been wheelchair-dependent since 2013, had developed progressive scoliosis beginning in 2016, and had lost the ability to perform activities of daily living independently before this admission.

During the intensive care stay, tracheostomy was performed because of extubation failure. After transfer to the general nursing unit, he remained dependent on mechanical ventilation and showed severe malnutrition. Nutritional Risk Screening 2002 score was 4, indicating high nutritional risk. Physical examination showed marked muscle atrophy, with proximal limb strength graded as 1 and distal limb strength graded as 2-. Moderate spinal curvature restricted chest wall expansion.

Skin assessment identified stage II pressure injuries over the sacrococcygeal region (9 cm x 10 cm) and bilateral ankles (1 cm x 2 cm). These injuries were considered related to prolonged immobility and poor perfusion during the acute phase. Chest radiography showed bilateral pneumonia and significant scoliosis. Arterial blood gas assessment indicated chronic carbon dioxide retention, with carbon dioxide combining power of 43.8 mmol/L. The patient was alert but unable to speak because of the tracheostomy. Communication was established through head nodding and gestures.

Timeline

On the day of admission, the patient experienced an out-of-hospital sudden cardiac arrest; bystander CPR performed by his family resulted in return of spontaneous circulation, and he was admitted to the intensive care unit. During the ICU stay, he failed extubation and underwent tracheostomy. After stabilization of vital signs, he was transferred to the general nursing ward, where assessments identified ventilator dependence, bilateral pneumonia, severe malnutrition, moderate scoliosis, stage II pressure

injuries, and chronic carbon dioxide retention. Individualized nursing interventions including sequential airway clearance, enteral nutrition support, pressure injury protection, and gradual standing-bed training were initiated and adjusted according to his respiratory tolerance, oxygenation status and comfort. Caregiver education on tracheostomy care, suctioning, ventilator inspection and emergency management was delivered throughout the ward stay using demonstration and return demonstration. When hemodynamics remained stable, airway patency was sustained, and the family achieved proficiency in required home care skills, the patient was discharged for home mechanical ventilation.

Nursing Assessment and Management

Individualized airway clearance

The first nursing priority was secretion clearance. The patient had four barriers to effective sputum clearance: respiratory muscle weakness, weak cough, a tracheostomy tube, and restricted chest movement from scoliosis. In this setting, suctioning removed secretions already near the artificial airway but could not reliably mobilize deeper bronchial secretions. The team therefore used a combined strategy consistent with DMD respiratory recommendations and neuromuscular airway clearance principles [5,8].

Continuous heated humidification was used to reduce mucus drying after tracheostomy. Airway gas was maintained at 37 degrees C with 100% relative humidity when clinically feasible, following pediatric tracheostomy care principles [7]. High-frequency chest wall oscillation was used before suctioning. The device was set at 300-500 cycles/min and used 1-3 times daily according to secretion volume, oxygenation, comfort, and tolerance. Each session was followed immediately by tracheal suctioning so that mobilized secretions were not left in the airway.

Tracheostomy dressing changes were performed twice daily and whenever dressings became wet or soiled. The stoma was checked for redness, maceration, secretion crusting, and early tissue overgrowth. When early overgrowth was observed, local cleansing and hypertonic saline dressing were used according to local practice. This point is reported as bedside experience, not as a general recommendation, because evidence for this exact dressing approach in pediatric DMD is limited.

Nutrition support and aspiration prevention

The patient had severe malnutrition and an NRS-2002 score of 4. In advanced DMD, nutritional problems may reflect dysphagia, reduced mobility, altered energy needs, constipation, gastroparesis, and feeding fatigue [3,9]. A nasogastric tube was inserted for nutrition and medication administration. Nursing care focused on calorie delivery, aspiration prevention, and tube-related skin protection.

During feeding and for 60 minutes afterward, the head of the bed was elevated to 30-45 degrees. Gastric residual volume was monitored every 4 hours according to unit protocol. The nasogastric tube fixation site was rotated, and a hydrocolloid barrier was applied to protect the nasal ala. Oral hygiene was

performed twice daily to reduce oral bacterial burden and the risk of microaspiration, consistent with pneumonia-prevention recommendations for ventilated patients [10].

Skin integrity and rehabilitation

Pressure injury care was shaped by the same problem as airway care: the patient's body could not be repositioned as if the spine and chest wall were normal. Turning was individualized according to scoliosis, bony prominences, respiratory mechanics, and comfort. Gel support pads were used to offload pressure while avoiding chest compression. Wound care followed pressure injury prevention and treatment principles, including reassessment, moisture control, pressure redistribution, and avoidance of further tissue trauma [11].

After hemodynamic stability was achieved, the team began electric standing-bed training. Training started at a 30-degree tilt for 20 minutes. The angle was increased according to orthostatic tolerance, oxygenation, respiratory comfort, and fatigue. The aim was modest: to preserve positional tolerance, reduce further deconditioning, assist circulation, and give the patient a different visual field during prolonged bed care.

Family education and discharge preparation

Discharge preparation started before discharge was imminent. Pediatric chronic home invasive ventilation guidelines emphasize caregiver training, equipment readiness, emergency planning, and coordinated follow-up before discharge [6]. For this patient, the practical target was clear: family members had to be able to act when the tube was blocked, secretions increased, or ventilator equipment failed.

Training covered suctioning, inner cannula care, recognition of tube blockage, emergency response steps, ventilator battery checks, circuit checks, and routine equipment maintenance. Teaching was delivered through demonstration, return demonstration, and repeated bedside coaching. Family readiness was judged by observed performance. The patient was also supported through gesture-based communication, reading, films, and other quiet activities compatible with ventilatory support.

Implications for Nursing Practice

Four practice points emerged from this case. First, airway clearance in advanced DMD with scoliosis should be managed as a sequence: humidify, mobilize, suction, reassess breath sounds and comfort, and then adjust frequency. Second, pressure injury prevention should be planned together with respiratory positioning because a skin-protective position may worsen chest expansion. Third, nutrition support should be paired with oral care, aspiration precautions, and tube-site protection. Fourth, discharge teaching should use return demonstration for high-risk skills rather than relying on verbal instruction alone.

Outcome

By discharge, the patient was hemodynamically stable and maintained airway patency with the individualized respiratory nursing plan. No ventilator-associated pneumonia was documented during the reported nursing period, and no further pressure-related skin deterioration occurred. Family caregivers completed bedside training in airway management and ventilator safety checks. Long-term post-discharge follow-up data were not available in the source record.

Discussion

This case shows how several familiar DMD problems can make one another harder to manage. DMD respiratory care guidance emphasizes surveillance, assisted cough, noninvasive ventilation when possible, and invasive ventilation when clinically required [4–6]. In this patient, cardiac arrest, extubation failure, pneumonia, and chronic carbon dioxide retention created a high-risk transition from intensive care to long-term ventilatory support.

The central nursing issue was not the tracheostomy tube alone. It was the combination of tracheostomy, weak cough, scoliosis, and pneumonia. Thoracic deformity limited chest expansion, and weak cough reduced the patient's ability to move secretions toward the tube. Heated humidification, mechanical secretion mobilization, and immediate suctioning formed a practical sequence. This approach is consistent with neuromuscular airway clearance literature, although this case cannot determine the optimal device setting [8].

Nutrition, aspiration prevention, and skin protection were also linked. Malnutrition can impair wound healing, while dysphagia and ventilatory dependence increase the consequences of aspiration [3, 9, 10]. Repositioning for pressure redistribution may also be limited by respiratory instability and spinal curvature. The care plan therefore relied on repeated bedside reassessment rather than a fixed schedule applied without modification.

Caregiver readiness was the final nursing domain. Children and adolescents discharged with chronic invasive ventilation require caregivers who can manage equipment and respond to airway emergencies [6]. In this case, education was treated as a clinical intervention. The family practiced suctioning, cannula care, equipment checks, and emergency steps at the bedside.

This report has limitations. It describes one patient from a single clinical setting and lacks long-term follow-up after discharge. Some interventions, including the local stoma dressing approach and standing-bed progression, were based on clinical judgement and local practice rather than comparative evidence. Even so, the case offers a practical care logic for nurses caring for adolescents with advanced DMD and overlapping respiratory, orthopedic, nutritional, skin, and family-training needs.

Patient Perspective

The patient communicated through gestures, head nods and nonverbal communication aids. He shared that he felt empowered accompanied by medical staff. Turning and suctioning brought discomfort,

though he understood these measures helped him breathe more easily. He expressed anxiety about going home with a tracheostomy and ventilator but felt reassured after watching his family repeatedly practice the care skills. He hoped to maintain comfort after discharge.

Conclusion

In this adolescent with advanced DMD, tracheostomy dependence and scoliosis changed the way basic nursing tasks had to be performed. Airway clearance, feeding, skin protection, rehabilitation, and family education were managed as connected problems rather than separate checklist items. This case supports a bedside nursing approach based on sequence-based airway care, respiratory-aware repositioning, aspiration-conscious nutrition, and return-demonstration caregiver training.

Declarations

Ethics approval: This case report involved a single patient retrospective analysis with non-invasive clinical nursing intervention, and no additional human trials or experimental operations were carried out. Therefore, institutional ethics review was waived by the ethics committee of our affiliated hospital.

Consent for publication: Written informed consent was obtained from the patient's legal guardian for publication of this case report and any accompanying images. A copy of the written consent is available for review by the Editor-in-Chief of this journal.

Patient anonymity: Identifying details have been minimized in this manuscript. Authors should verify that all dates, locations, and clinical details comply with the target journal's privacy policy.

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Data availability statement Data sharing is not applicable to this article due to patient confidentiality restrictions. The relevant clinical data described in this case report are included within the published article. Raw clinical records cannot be shared publicly to protect the privacy of the patient.

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