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Developing a Care Guideline for Patients with Duchenne Myotonic Dystrophy and Their Families: a Literature Review

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Abstract

Duchenne Muscular Dystrophy (DMD) is a life-threatening inherited disease in children, for which no effective therapies currently exist. Family members undergo emotional and socioeconomic strain while providing care for a child with Duchenne dystrophy. Therefore, there is an urgent need for patient- and family-centered care programs. The purpose of this study was to develop a comprehensive guideline to support families caring for individuals with DMD. A five-step review was undertaken as follows: defining the review question, setting the review objectives, searching databases to identify relevant studies, selecting studies according to set criteria, and extracting and analyzing data. In the third stage, a review of the existing literature was done using PubMed, CINAHL, Science Direct, Ovid, Embase, Pro Quest, Web of science and Google Scholar between 1991 and 2024. Researchers used the MESH keywords muscular dystrophy, Duchenne, comprehensive health care, and caregiver separately or in combination. The findings identified disease-related complications and corresponding care interventions that can be undertaken by family members. These interventions included pain management, promotion of muscle strength, assistance with activities of daily living, considerations related to medication use, cardiac management, respiratory care, gastrointestinal management (including nutrition and swallowing), psychosocial support, and management of endocrine and metabolic functions.
Since Duchenne dystrophy is chronic, self-care and the role of the family in these patients are very important. Family contributes significantly to preventing physical, psychological, and social problems in these patients and improves their quality of life.

Keywords: Muscular dystrophy, Duchenne, Comprehensive health care, Caregiver

Introduction

Muscular dystrophy (MD) refers to a group of more than 30 genetic diseases characterized by progressive weakness and degeneration of skeletal muscles that control movement. Some forms of MD are seen in infancy or childhood, while others may not appear until middle age or later [1]. These disorders differ in distribution and severity of muscle weakness, with certain forms also affecting cardiac muscle, as well as in age of onset, rate of progression, and pattern of inheritance [2]. Duchenne Muscular Dystrophy (DMD) is an important Dystrophy and a devastating inherited disease in children with no effective therapies. DMD is the most prevalent neuromuscular disorder, affecting up to 1/3600 male births worldwide. DMD is an X-linked degenerative disease and affects approximately one in 3,500 to 5,000 live male births [3]. DMD is associated with mutations such as deletions (65%), duplications (6%–10%), small mutations (10%), or other smaller rearrangements [4]. These mutations disrupt the open reading frame of RNA. These mutations lead to a loss of dystrophin protein expression, resulting in severe muscle wasting, respiratory and cardiac failure, and death before the age of 30 [5].

DMD is characterized by progressive degeneration and loss of skeletal muscle, leading to motor milestone delay and loss of ambulation, generally before age thirteen. Gradually, progressive cardiomyopathy is uniformly present. Respiratory muscle disease causes early respiratory failure. The disease progresses very quickly and usually the patients necessitate a wheelchair at the age of 10 [6]. The average age of diagnosis is usually four, when the first symptoms appear. Diagnosis confirmation allows the initiation of proper interventions and provision of educational and information support, and adequate genetic counseling for families [7].

There is no specific cure available for DMD, and the current interventions are based on the prevention and management of complications. However, the researchers are working hard to develop a possible therapy to reduce both primary and secondary pathologic effects [8]. Treatment is supportive and may include therapies such as physical, respiratory, and speech therapy; orthopedic appliances for support; corrective orthopedic surgery; and medications including corticosteroids, anticonvulsants, immunosuppressants, and antibiotics. Some individuals may need assisted ventilation to treat respiratory muscle weakness or a pacemaker for cardiac abnormalities [2].

Since these patients have many complications and need constant care, the role of families in taking care of these patients really matters. Families of children with a DMS go through significant caring challenges in dealing with the condition [9].

When DMD is diagnosed, families are informed that it is an inherited disorder and that the affected boy's sisters and cousins have a high risk of being carriers [10]. The diagnosis poses numerous challenges for parents. Mothers, in particular, have the additional burden of realizing that they may be the unsuspecting carriers of the mutation accounting for the disorder. Therefore, as the disease progresses, mothers may develop an attitude of self-blame. Both parents may react with feelings of disbelief, denial, anger, anguish, anxiety, guilt, fear, confusion, powerlessness, rejection, and parent/child-related stress [11].

Family members undergo emotional, social, and economic strain while providing care for a child with DMD. Therefore, the necessity for comprehensive care programs for patients and their families is clearly recognized. This study aimed to produce a guideline that can serve as a reference framework for families

Materials and Methods

Protocol

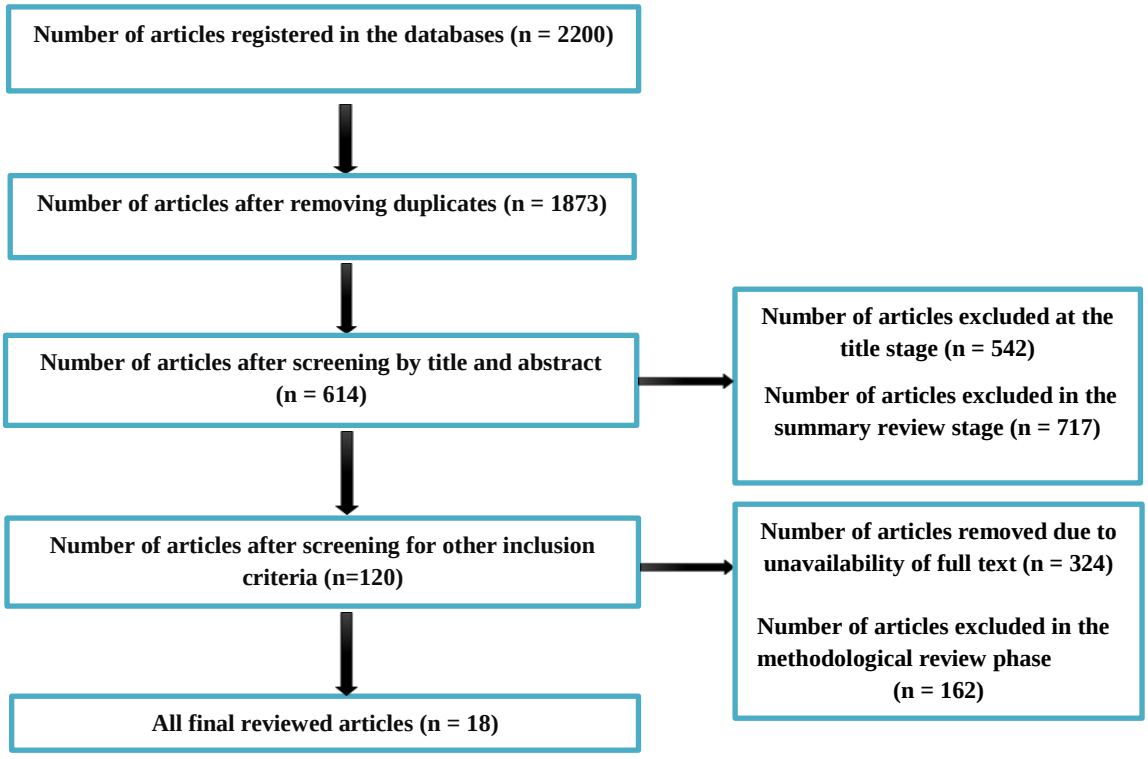
A five-step review was conducted as follows: defining the review question, setting the review objectives, searching databases to identify relevant studies, selecting studies according to set criteria, and extracting and analyzing the data.

Eligibility criteria

Study selection followed a three-stage screening: title review, abstract screening, and full-text assessment. Inclusion criteria were as follows:

- Studies Published during 1991-2024
- Studies published in English
- Studies relevant to the same subject
- studies available in full text

A total of 1,334 articles were retrieved from eight databases after removing duplicates. Following screening of titles, abstracts, and full texts based on the predefined criteria, 18 articles were included in the final analysis. Figure1. Systematic review process based on the PRISMA model.



Information sources

In the third stage, the existing literature was reviewed in PubMed, CINAL, Science Direct, Ovid, Embase, Pro Quest, Web of science and Google Scholar databases between 1991 and 2024.

Search strategy

Researchers used the MESH key words Muscular dystrophy, Duchenne, Comprehensive health care, caregiver separately or in combination.

Results and Discussion

The family is the preliminary and fundamental unit of a society, responsible for providing correct and appropriate health care to patients. Family-centered care includes examining the family, family participation in care and information exchange between the treatment team and the family [12]. Given that this approach is low-cost and available and has positive effects, it can be used as a scientific solution for participation. It should be used by most patients and families, especially in families with a child suffering from

a chronic disease, including DMD [13]. Since these patients with their chronic disease face many complications, the family has important role in managing and controlling these complications. So in this section, the complications with the interventions that the family can make are given.

1. Pain management

A growing number of studies show that chronic pain is a common symptom for people afflicted with neuromuscular diseases (NMD). In a recent study of 55 patients aged 12-18 living with Duchenne or spinal muscular atrophy (SMA), 55% complained of mild to moderate, persistent, or chronic pain [14]. Previous studies reported that 54-80% of patients living with Duchenne suffer from mild to moderate aching pain for more than several hours daily [15].

Chronic pain may be common, even though it is not the primary concern of patients or doctors. In some cases, pain can be the leading problem with adverse effects on function and quality of life [16].

2. Tips to Help Avoid Pain

2.1. Ensure Adequate Hydration

Dehydration is known to exacerbate various types of pain. It may contribute to headaches, worsen back pain, and increase the risk of genitourinary (GU) stone formation. Adequate water intake is essential for maintaining overall health [17].

2.2. Maintain a Healthy Diet

Consumption of a balanced and healthy diet supports proper digestion, helps prevent constipation, and assists in weight management, which may reduce certain types of musculoskeletal pain [18].

2.3. Promote Physical Activity, Flexibility, and Proper Alignment

Ongoing physical therapy and the use of ankle–foot orthoses (AFOs) can help maintain flexibility and proper body alignment, thereby contributing to pain prevention [19].

2.4. Encourage Relaxation

Stress can trigger or worsen pain. Incorporating regular relaxation practices into daily routines, such as walking, reading, listening to music, gentle stretching, or meditation, may support pain management [18].

2.5. Support Regular Family Interaction

Regular family engagement and effective communication may enhance psychological resilience and reduce stress, thereby helping to alleviate pain-related symptoms [17].

2.6. Ensure Appropriate Use of Assistive Equipment

Improperly fitted ankle–foot orthoses, inadequate spinal support, or unsuitable wheelchairs may cause or exacerbate pain. Regular assessment and appropriate prescription of assistive devices are essential. Consistent use of these devices is also important. Follow-up by physical therapy, physical medicine and rehabilitation services helps ensure optimal support and pain prevention [20].

2.7. Ensure Adequate Sleep

Research showed a complex bidirectional relationship between sleep and pain, with each potentially exacerbating the other. Effective management strategies should, therefore, address both sleep quality and pain control [16].

2.8. Optimize Respiratory Function

Individuals with DMD should receive annual lung function assessments and consultation with a pulmonologist. Reduced oxygen levels, due to conditions such as obstructive sleep apnea or hypoventilation, can lead to sleep-disordered breathing, negatively impacting sleep quality.

Maintaining optimal respiratory function during sleep is essential for overall health.

Help Promote Muscle Strength

The overall aim of musculoskeletal care is to maintain motor function for as long as possible, minimize joint contractures, maintain a straight spine, and promote bone health [21]. Scoliosis usually develops during the phase of constant wheelchair dependence, shows rapid progression during pubertal growth spurt and adversely affects respiratory function, feeding, seating and comfort [22]. A spinal brace (jacket) does not prevent the progression of scoliosis but may be useful in postural management, especially in cases where spinal surgery is contraindicated or not acceptable to the patient [13]. Boys with muscle weakness develop stiffness in some joints - such as the ankle - and curvature of the spine (scoliosis), usually in early adolescence that can be corrected with surgery [6]. For ambulatory children, night splints should be provided when there is loss of dorsiflexion at the ankle, loss of a normal grade of dorsiflexion and before the foot can only achieve plantar grade [8].

Help Promote Activities of Daily Life

An important goal of patient management is the maintenance of activities of daily living (ADL) as long as possible. Patients with DMD develop progressive weakness, contractures, and spinal deformity. They may also experience restrictive lung disease, cardiomyopathy, and variable degrees of cognitive impairment - all contributing to progressive impairment in the ability to complete (ADL) [9].

Physiotherapy can help through:

• Providing information on how to avoid overexertion

• maintaining correct foot position through:

a) Daily ankle and foot stretches that can be performed at home

b) Use of below-knee braces, if appropriate

• providing counseling on recreational and leisure activities that support the maintenance of functional abilities

• providing an accessible environment at home and school. Stairs are difficult for boys with weak muscles. One-story houses and schools, or schools with elevators are recommended [13, 24].

Consideration for using drugs

Promoting bone health is crucial for patients treated with corticosteroids. This includes dietary guidance on calcium and vitamin D, and supplementation if plasma vitamin D levels are low. Use of ACE inhibitors and beta-blockers is recommended for patients with early cardiomyopathy [22].

One side effect of Deflazacort use, combined with reduced physical activity such as prolonged wheelchair use, is bone calcium loss leading to osteoporosis. This may increase the risk of fractures. Alendronate has successfully helped osteoporosis in adult women [16].

Cardiac Management

Cardiovascular complications are a leading cause of disease-related morbidity and mortality among individuals with DMD. Dystrophin deficiency in the heart manifests as a cardiomyopathy. As the disease progresses, the myocardium fails to meet physiological demands, and clinical heart failure develops. The failing myocardium is also at risk of life-threatening rhythm abnormalities [23]. Cardiac involvement in DMD most commonly includes dilated cardiomyopathy. This condition is characterized by a dilated left ventricle and reduced ejection fraction on echocardiography. However, hypertrophic cardiomyopathy and conduction abnormalities can also occur.

For an early detection of asymptomatic cardiomyopathy in patients with DMD, a regular assessment is needed. The annual assessment of cardiac function includes an electrocardiogram (ECG) and echocardiogram [24]. Guidelines on heart failure should be followed for pharmacological treatment. Pharmacological treatment, including angiotensin-converting enzyme (ACE) inhibitors with or without β-blockers, for asymptomatic and symptomatic

cardiomyopathy in DMD reduces both morbidity and mortality. A cardiologist should be consulted before all surgical procedures [25].

Respiratory Considerations

Respiratory complications are a major cause of morbidity and mortality in patients with DMD. Complications include respiratory muscle fatigue, mucus plugging, atelectasis, pneumonia, and respiratory failure. If left untreated, patients are at risk of severe dyspnea, lengthy hospital admissions due to atelectasis or pneumonia, and death due to respiratory arrest or respiratory-induced cardiac arrhythmias [26].

Skeletal muscle fiber degeneration and loss of chest wall and diaphragm muscles lead to difficulties with airway clearance and ventilation. Progressive respiratory muscle failure limits the ability to inhale and exhale fully and forcefully, causing the forced vital capacity (FVC) to decrease, the production of a typical restrictive respiratory pattern [23].

Decreasing respiratory reserve in teenagers leads to sleep-disordered breathing, with REM-sleep-related hypoxemic dips and obstructive apneas. The resulting symptoms include morning drowsiness, poor appetite, headaches, nausea, fatigue, tiredness, poor concentration at school, and failure to thrive. Additionally, there can be reduced coughing ability or overt respiratory failure in the course of ‘‘minor’’ respiratory infections, [25] and maintaining healthy lungs. It is important as muscle weakness affects the muscles used for breathing. A smoke-free environment, use of flu vaccines, and regular assessment of lung function at clinic visits all matter [24].

Mechanical ventilation is the main intervention affecting survival in DMD, improving the median survival of patients to ~27.0 years, compared to ~19.0 years without ventilation. Disease management strategies also affect pulmonary function. Patients who have undergone scoliosis repair tend to have better pulmonary function. The same applies to those using aggressive airway clearance techniques. Additionally, patients receiving ventilator support and corticosteroid therapy show improved lung function compared to those not receiving these treatments [27].

Gastrointestinal Management: Nutrition, Swallowing and other Issues

Nutritional intake is a crucial aspect of management. Boys with DMD require fewer calories than average healthy children. Ambulatory boys need about 80%, while non-ambulatory boys need about 70% [27]. It is important to individualize recommendations based on physical ability and ambulatory status. Nutritional counseling should ensue from the outset, well before corticosteroids are initiated. General principles that underlie a low glycemic index diet may help with weight control and prevention of hyperinsulinemia [28]. These include avoidance of simple sugars, portion control, increased fiber and whole grains, and limited fat intake [29].

These include obesity during the late ambulant phase, especially in corticosteroid-treated individuals, and severe wasting in the spinal surgery postoperative period and the late teenage. Regular weight monitoring and dietary advice to avoid obesity should be offered to all DMD patients, especially when treated with daily corticosteroids [30]. Young adults with DMD may have chewing and swallowing difficulties, prolonged mealtimes, and episodes of choking on food, which contribute to fear of eating and failure to thrive [31].

Also, gastrointestinal complications such as constipation and gastroesophageal reflux are highly prevalent in this population and can significantly impact the quality of life, nutritional status, and overall health [13]. Constipation may result from reduced mobility, low fluid intake, and side effects of medications. While reflux can lead to discomfort, poor appetite, and the risk of aspiration. Effective management requires a multifaceted approach, including dietary modifications such as increased fiber, adequate hydration, and smaller, frequent meals,

encouragement of physical activity as tolerated, and timely medical interventions when necessary [9-12]. Regular monitoring, individualized care plans, and education for patients and caregivers are essential to prevent complications, support adequate nutrition, and maintain overall gastrointestinal health [28].

Psychosocial Management

Providing comprehensive care for individuals with DMD should include surveillance. It should also address the psychosocial effects of the disease across the lifespan, which now extends well into adulthood for many patients. Many people with DMD are well adjusted to their conditions and their surrounding world, and lead independent, productive lives [32].

It is helpful to encourage participation in recreational and leisure activities tailored to an individual's interests and functional abilities, which may include swimming, cycling (with or without adaptations), adaptive skiing, or wheelchair hockey [33].

Endocrine/Metabolic Function Management

The most important endocrine alteration in patients with DMD/BMD is hypogonadism, which has been related to dystrophies. The consequences are delayed puberty, growth failure, osteoporosis, and metabolic abnormalities [34]. Testosterone levels decline with aging is associated with decreased muscle mass and strength in healthy subjects. Testosterone treatment increases muscle mass and strength in older hypogonadal men. The importance of testosterone in the maintenance of muscle mass is critical, and testosterone therapy should be considered when hypogonadism is present [8,35].

Another key metabolic alteration in muscular dystrophies may be insulin resistance and obesity. However, only insulin resistance has been evident in myotonic dystrophy [33]. Medications, such as metformin, could be considered in selecting cases in whom weight gain is severe and insulin resistance or glucose intolerance are present. Metformin is an insulin-sensitizing agent that is effective in type 2 diabetes and insulin resistance, and may result in weight loss [39]. A case series of boys with DMD on corticosteroids with extreme weight gain and insulin resistance was treated with metformin at Cincinnati Children's Hospital Neuromuscular Center, and showed short-term weight loss or slowed rate of weight gain, and improved body mass index [40].

Conclusion

This article highlights the critical role of family-centered self-care in the management of DMD as a chronic and progressive disease. This study emphasizes low-cost, feasible, and preventive strategies that families can implement. These strategies provide practical knowledge to help reduce preventable complications. They also aim to improve patients' physical, psychological, and social well-being. The findings highlight the importance of empowering families through education and support. This empowerment can significantly enhance patients' quality of life and reduce the burden on healthcare systems. From a policymaking perspective, the results suggest that integrating family-based self-care training and support programs into national healthcare plans and community health services could be a cost-effective and sustainable approach to DMD management. Such policies may lead to improved long-term outcomes for patients and more efficient use of healthcare resources.

Conflicts of Interest

None to declare

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