Ascertaining the Complex Nature of Dealing with a Terminal Illness of a Child with DMD and its Effects on Those Who Are Involved in Caregiving

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Parmis Parsamanesh

Mentor: Dr. Mykhailo Vysochyn

Saint James School of Medicine, Anguilla Campus
**Abstract**

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<td>• DMD is a genetic disorder that leads to progressive muscle degeneration and muscle weakness due to alteration of the Dystrophin protein. Studies reveal that there are minimal support systems in place for the families and caregivers of patients with DMD, which further amplifies their responsibilities.</td>
<td>• To understand the direct and indirect impacts of the caregivers of patients diagnosed with DMD.</td>
<td>• Using the PubMed database and a specific combination of MeSH terms, 93 articles were reviewed, 8 of which met the inclusion criteria. The articles were coordinated into a table and further analyzed for their significance to this literature review.</td>
<td>• A review of the literature revealed that the burden on caregivers of patients with DMD is significant with a reduced HRQoL, leading to decreased psychological well-being as well as an increased financial burden on the family.</td>
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</table>
Introduction: Why is this research important?

- Genetic disorder
- No cure, early diagnosis can help slow the progression of muscle weakness.
- Mental well-being of families and caregivers of patients
Introduction: Caregiver Burden

- Health Related Quality of Life
- Psychological Well-Being
- Financial Burden
The search was conducted using the PubMed (Medline) database. To retrieve articles, the following MeSH combination of terms was used: Duchenne muscular dystrophy [ti] AND caregivers [tw] AND impact [tw]. Papers were retrieved in English only. Each author reviewed the articles independently to determine if all inclusion criteria was met. The articles that met the inclusion criteria, were organized into the observation data tables 1-3.

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<th>There is congruity between the stated physiological perspective and the research methodology</th>
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| There is congruity between the research methodology and the research question of objectives | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ |
| There is congruity between the research methodology and the methods used to collect data | ☐ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ☐ | ✔️ |
| There is congruity between the research methodology and the representation and analysis of data | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ |
| There is congruity between the research methodology and the interpretation of results | ☐ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ |
| The research is ethical according to current criteria, or, for recent studies, there is evidence of ethical approval by an appropriate body | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ |
| Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of the data | ✔️ | ✔️ | ✔️ | ✔️ | ✔️ | ☐ | ✔️ | ✔️ |
• Duchenne Muscular Dystrophy
• DMD
• Mental health
• Psychological well-being
• Muscular dystrophy
• Parents' caregivers
• Family burden/care burden
## Results: Health Related Quality of Life

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<td>Quality of life and informal care burden associated with Duchenne muscular dystrophy in Portugal: the COIDUCH study [7]</td>
<td>48 DMD caregivers (8 ambulatory, 38 non-ambulatory patients)</td>
<td>Caregivers to patients with DMD registered through Portuguese Neuromuscular Association; Face-to-face interviews with trained interviewers followed by caregivers answering a customized questionnaire.</td>
<td>COI, HRQoL, burden of caregivers specifically related to work time missed (absenteeism), impairment while working (presenteeism), overall work impairment (combined absenteeism and presenteeism), and activity impairment (daily activities).</td>
<td>EuroQol-5D (EQ-5D-3L), WPAS-CH, Wilcockson and Kocalski-Wallis tests.</td>
<td>The mean reported daily activity impairment was 60%. Caregivers of non-ambulatory patients reported a mean daily activity impairment of 64%. Caregivers of non-ambulatory patients with either full time or non full-time ventilation support presented a higher daily activity impairment, 77%, compared to patients without ventilation support, 57%. Extreme problems were faced in self-care, mobility and usual activities decline. Work impairments of 30.5%.</td>
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<td>Quantifying the burden of caregivers in Duchenne muscular dystrophy [4]</td>
<td>Multinational study, 779 caregivers</td>
<td>Caregivers to eligible patients were invited to complete a questionnaire online.</td>
<td>To investigate the subjective caregiver burden associated with DMD, prevalence of anxiety and depression, and caregiver health related quality of life.</td>
<td>EuroQol EQ-SD-3L (EQ-5D), a Visual Analogue Scale (VAS), and the SF-12 Health Survey (SF-12)</td>
<td>Approximately half of the caregivers reported being moderating or extremely anxious or depressed (p&lt;0.001 when compared to general population). A large proportion of DMD caregivers reported having pain or discomfort and problems performing usual activities. Nearly 30% of caregivers estimated the annual household cost burden at over $5000 (p &lt; 0.006).</td>
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<td>Characterizing the quality-of-life impact of Duchenne muscular dystrophy on caregivers a case-control investigation [7]</td>
<td>566 DMD caregivers, 584 non DMD comparison caregivers</td>
<td>A web-based survey included DMD caregivers and a nationally representative comparison group of parents of children without DMD stratified by Child Age Group.</td>
<td>To examine the impact of DMD on family member caregivers in terms of QoL, life stress, and indirect costs.</td>
<td>PROMIS-10 General Health, NeuroQOL Positive Affect and Well-Being, The Ryff Environmental Mastery, and the Centers of Disease Control (CDC) Healthy Days Care Module</td>
<td>DMD caregivers reported worse physical health, mental health, positive affect, environmental mastery, stressful life events, and difficulty paying bills than comparison caregivers.</td>
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<td>Drivers of caregiver impact in Duchenne muscular dystrophy: a cohort study [9]</td>
<td>586 DMD Caregivers</td>
<td>Eligible participants were age &gt;18 or older, able to complete an online questionnaire, and were providing caregiving support to a family member with DMD at least two years old, usually their son.</td>
<td>The association between specific psychosocial factors and impact proxies in a sample of DMD caregivers. The psychosocial factors examined included demographic, QoL, life stress, resilience, COVID-related, reserve-building, and cognitive appraisal approach.</td>
<td>Person-reported outcomes (PROs), PROMIS-10 General Health, NeuroQOL Positive Affect and Well-Being, The Ryff Environmental Mastery, Urban Life Stress Inventory, Work Productivity and Activity Impairment measure, UHIN, The CDC Healthy Days Core Module, Current-Reserve-Building Measures, QoL appraisal, and ANOVA</td>
<td>As the child's disability progresses, DMD caregivers experience an increased impact as a function of their own health and environmental mastery, and of levels of life stress. More impacted caregivers experienced a worsened impact during the COVID pandemic. Caregivers' engagement in passive-media consumption was associated with worsened impact, as was a cognitive pattern that focused on the negative. Stress variables from high impact group, revealed that difficulty paying bills and hours missed from work was most prominent and worsened compared to low-impact group.</td>
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<td>Measuring Duchenne muscular dystrophy impact: development of a proxy-reported measure derived from PROMIS item banks [16]</td>
<td>521 DMD caregivers</td>
<td>Web-based study following telephone interviews as a protest.</td>
<td>Fatigue support, strength impact, cognitive function, upper extremity function, positive affect, negative affect, sleep-decive symptoms, and mobility.</td>
<td>PROMIS item banks</td>
<td>Caregivers presented with controllable health conditions, with the most prevalent being back pain, depression, insomnia, and arthritis.</td>
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<td>A qualitative study on the impact of care for an ambulatory individual with nonsense mutation Duchenne muscular dystrophy [12]</td>
<td>10 DMD caregivers</td>
<td>Patients with DMD from Germany, Italy, the UK, and the US recruited through national registries. Caregivers invited to complete an online questionnaire.</td>
<td>The impacts and challenges experienced by caregivers of ambulatory individuals before treatment with Ataluren.</td>
<td>PAG and MAXQDA</td>
<td>Caregivers reported proximal impacts such as physical, emotional and daily impacts that affected their work, relationships, and social life. Disrupted sleep patterns were present due to care for DMD child at night. Several caregivers experienced grief/sadness upon their child's diagnosis and watching them deteriorate. Caregivers were diagnosed with depression, experienced anxiety and a high load of stress. After Ataluren, DMD patients experienced positive changes that had direct impacts on caregivers. DMD caregivers were less anxious, back pain subsided, increased social life, able to go to work, and overall a positive impact of ataluren on their quality of life because they could see their son improve.</td>
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Results: Psychological Well-being

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<td>EuroQol-5D (EQ-SD-5L), WPAL-GH, Wilcoxon and Kruskal-Wallis tests.</td>
<td>The mean reported daily activity impairment was 66.4. Caregivers of non-ambulatory patients reported a mean daily activity impairment of 66.4%. Caregivers of non-ambulatory patients with either full time or non-full-time ventilation support presented a higher daily activity impairment, 77%, compared to patients without ventilation support, 57%. Extreme problems were faced in self-care, mobility, and usual activities decline. Work impairment of 30.5%. Approximately half of the caregivers reported moderate or extremely anxious or depressed (p&lt;0.001 when compared to general population). A large proportion of DMD caregivers reported having pain or discomfort and problems performing usual activities. Nearly 30% of caregivers estimated the annual household cost burden at over $5000 (p&lt;0.006).</td>
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<td>The association between specific psychosocial factors and impact profiles in a sample of DMD caregivers. The psychosocial factors examined included demographic, QOL, life stress, resilience, COVID-related, reserve-building, and cognitive appraisal approach</td>
<td>Person-reported outcomes (PROs), PROMIS-10 General Health, EuroQoL Positive Affect and Well-Being, The Ryff Environmental Mastery, Urban Life Stress Inventory, Work Productivity and Activity Impairment measure, USNH, The CDC Healthy Days Core Module, Current-Reserve Building Measure, QOL appraisal, and ANOVA</td>
<td>As the child’s disability progresses, DMD caregivers experience of impact varies as a function of their own health and environmental mastery, and of levels of life stress. More impacted caregivers experienced a worsened impact during the COVID pandemic. Caregivers engagement in passive-media consumption was associated with worsened impact, as was a cognitive pattern that focused on the negative. Stress variables from high impact group, revealed that difficulty paying bills and hours missed from work was most prominent and worsened compared to low-impact group.</td>
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## Results: Financial Burden

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<td><strong>The burden of Duchenne muscular dystrophy</strong> [5]</td>
<td>770 patient-caregiver pairs Germany = 173 Italy= 122 United Kingdom= 191 United States = 284</td>
<td>Eligible patients and one of their caregivers (e.g., parent) were invited to complete a questionnaire online</td>
<td>To estimate the total cost of illness and economic burden of DMD to society and caregiver households.</td>
<td>Health Utilities Index and EuroQol EQ-SD</td>
<td>The total society burden was estimated at between $82,120 and $120,910 per patient and increased with disease progression. The mean annual household burden was estimated between $58,440 and $71,900.</td>
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<td><strong>Interplay of disability, caregiver impact, and out-of-pocket expenditures in Duchenne muscular dystrophy: a cohort study</strong> [8]</td>
<td>566 DMD Caregivers</td>
<td>A web-based survey</td>
<td>The association between caregiver impact domains and out of pocket expenditures, and the presence of clusters in caregivers on the basis of DMD-related disability domains in the patients for whom they provided caregiving support</td>
<td>DMD caregiving Impact Measure, PROMIS-derived parent-proxy (PPP), Cohens criteria, Hierarchical cluster analysis, and Latent Profile Analysis</td>
<td>Higher out-of-pocket expenditures were generally associated with worse impacts on the caregivers. Several expenditures (e.g., kitchen, bathroom, scooter) were associated with lower impact. Caregivers with lower impact reported the highest mobility, cognitive, and upper extremity functioning of their DMD care recipients. The highest caregiver impact was driven by their care recipients negative affect and fatigue.</td>
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<td><strong>Drivers of caregiver impact in Duchenne muscular dystrophy: a cohort study</strong> [9]</td>
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<td>As the child’s disability progresses, DMD caregivers experience less impact but that is not a function of their own health and environmental mastery, and of levels of life stress. More impacted caregivers experienced a worsened impact during the COVID pandemic. Caregivers engagement in passive-media consumption was associated with worsened impact, as was a cognitive pattern that focused on the negative. Stress variables from high impact group, revealed that difficulty paying bills and hours missed from work was most prominent and worsened compared to low-impact group.</td>
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Discussion: Health Related Quality of Life

- Caregivers must learn to cope with a DMD diagnosis, its progressive and pervasiveness, and the knowledge of the terminal aspect of this illness, meaning they will be losing their loved ones.

- This, in turn, reduces their physical, emotional, mental, and social functioning over time.
Discussion: Psychological Well-Being

- Studies have shown the psychological burden increased significantly as the child being cared for became non-ambulatory. Specifically, depression was recorded in approximately 70% of caregivers.¹

- As a result, caregivers have a challenging time providing consistently as they are not getting the proper mental care they require.
Discussion: Financial Burden

- The mean annual household burden of DMD was calculated using factors such as income loss, the monetary value of lost leisure time, and reduced quality of life, estimated at between $58,440 and $71,900.

- This terminal illness has many costs to consider and is associated with a significant economic burden.⁵
Recommendations

• Better establish different social interactions, support groups for the caregivers, and making sure we are assessing their psychological well-being and their different needs. In addition, when the child is in a therapy session, making sure the caregiver knows how to properly lift the child, and provide other physical assistance that can take a toll on the caregiver’s health. Ensure there are policy changes and put pressure on insurance companies to help with the financial burden.
Limitations

- There is not enough research done on the caregiver burden as it pertains directly to a child living with a terminal illness.
- There is a lot of research on caregiver burden and the profound impact of caring for a loved one can have but most of it is tied to caring for an elderly parent or someone with dementia.
- While the caregiver burden for such patients must not be minimized in any way, the few articles that compared the two really pointed out that the caregiver burden when someone is caring for a child is significantly increased specifically in the psychological well being quality of life factor, likely because a parent would not expect their child to have to suffer through that much pain.
Future Research

• Future research should be conducted in evaluating the success of support groups geared toward reducing caregiver burden and comparing Duchenne Muscular Dystrophy to other muscular dystrophy disorders pre- and post-diagnosis.

• It is also important to make sure we include patients of all ages and evaluate caregivers of all ages.

• We can also make sure to evaluate patients within the United States so that they all share the same health care system and benefits that are provided, rather than including other countries into the research.
The Importance of Caregiver Burden

• From our study, we conclude that researching and raising awareness regarding caregiver burden is just as significant as the health of the patient. Unfortunately, although the negative impacts of being a caregiver may seem obvious, not much action has been taken to improve the situation.

• It is vital for the government and health care system to take action to implement sufficient support systems to better assist in reducing the burden caregivers experience.


Ascertaining the Complex Nature of Dealing with a Terminal Illness of a Child with DMD and its Effects on Those Who Are Involved in Caregiving

Researchers: Adelina Balidemaj, Parmis Parsamanezh; Mentor: Dr. Mykhailo Vysochyn
Department of Basic Sciences, Saint James School of Medicine, Anguilla AL-2640

Abstract
Objective: To understand the direct and indirect impacts of caregivers of patients diagnosed with Duchenne’s Muscular Dystrophy (DMD).

Methods: Using the PubMed database and specific combination of MeSH terms, 93 articles were reviewed, 8 of which met the inclusion criteria.

Conclusion: A review of the literature revealed that the burden on caregivers of patients with DMD is significant with a reduced HRQoL, leading to decreased psychological well-being as well as an increased financial burden.

Introduction
DMD is a genetic mutation of the gene located on the short arm of the X chromosome (Xp21.2).1,2,5,6 It is one of the most frequent forms of muscular dystrophy that causes progressive muscle weakness due to the production of dystrophin, and currently there is no cure.7 The physical, mental, and social well-being impacts of the caregivers, remain unrecognized and unknown. It has been shown that providing informal care is associated with serious adverse health effects for the caregiver, such as anxiety, depression, social isolation, and financial deprivation.4

Methods
The search was conducted using the PubMed (Medline) database. To retrieve articles, the following MeSH combination of terms was used: Duchenne muscular dystrophy [ti] AND caregivers [tw] AND impact [tw]. Each author reviewed the articles independently to determine if all inclusion criteria were met.

Conclusion
The studies presented in this literature review elaborate on the effect of HRQoL, psychological well-being, and financial burden on the caregivers of patients with DMD. They all indicate that this illness has had a significant impact on the different aspects of their lives. There is evidence of a reduced HRQoL, which causes decreased psychological well-being due to the accompanying anxiety and depression and a financial burden that intensifies with the progression of this disease.

Discussion
Health Related Quality of Life: Caregivers must learn to cope with a DMD diagnosis, its progressive and pervasiveness, and the knowledge of the terminal aspect of this illness, meaning they will be losing their loved ones. This, in turn, reduces their physical, emotional, mental, and social functioning over time.

Psychological well-being: Studies have shown the psychological burden increased significantly as the child being cared for became non-ambulatory. Specifically, depression was recorded in approximately 70% of caregivers. As a result, caregivers are having a challenging time providing consistently as they themselves are not getting the proper mental care they require.

Financial burden: The mean annual household burden of DMD was calculated using factors such as, income loss, the cost of care, and the loss of productivity. Therefore, this financial burden: Caregivers must learn to cope with a DMD diagnosis, its progressive and pervasiveness, and the knowledge of the terminal aspect of this illness, meaning they will be losing their loved ones. This, in turn, reduces their physical, emotional, mental, and social functioning over time.

Future Considerations and Limitations
Further exploration of the function and availability of support programs such as therapy will allow caregivers to focus on their mental health and reduce the negative impacts of taking responsibility for a patient with a terminal illness may cause (i.e. anxiety, depression) is warranted, as there is a lack of research currently dedicated to the effectiveness of these interventions at addressing caregiver burden.

References