

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

Adelina Balidemaj

Parmis Parsamanesh

Mentor: Dr. Mykhailo Vysochyn

Saint James School of Medicine, Anguilla Campus



Abstract

Background

- 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.

Objective

- To understand the direct and indirect impacts of the caregivers of patients diagnosed with DMD.

Methods

- 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.

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 on the family.



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

Wheelchair Use



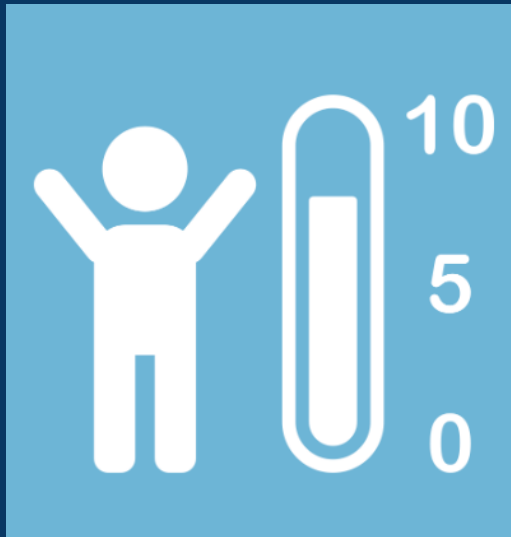
About 3 in 10 males (29%)
with DMD ages 5-9



About 8 in 10 males (82%)
with DMD ages 10-14



Introduction: Caregiver Burden



**Health Related
Quality of Life**



**Psychological
Well-Being**



**Financial
Burden**



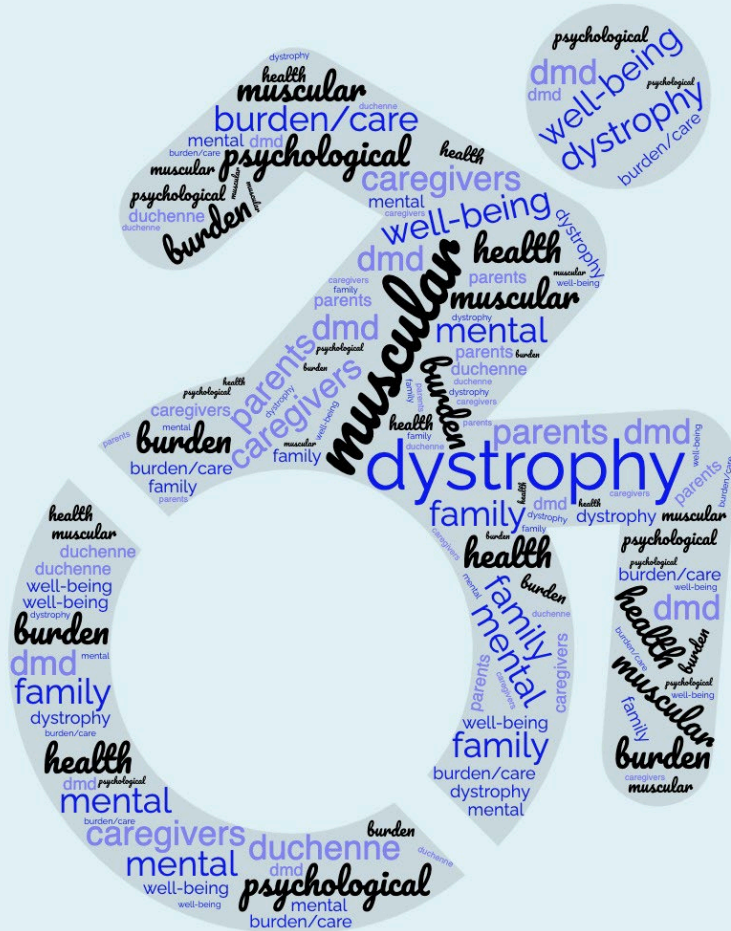
Methods

- 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]. 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.

	Study 1 Andreozzi, 2022 [1]	Study 2 Landfeldt, 2015 [4]	Study 3 Landfeldt, 2014 [5]	Study 4 Schwartz, 2021 [7]	Study 5 Schwartz, 2022 [8]	Study 6 Schwartz, 2022 [9]	Study 7 Schwartz, 2021 [10]	Study 8 Williams, 2021 [12]
There is congruity between the stated physiophysical perspective and the research methodology	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
There is congruity between the research methodology and the research question of objectives	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
There is congruity between the research methodology and the methods used to collect data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
There is congruity between the research methodology and the representation and analysis of data	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
There is congruity between the research methodology and the interpretation of results	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
The research is ethical according to current criteria, or, for recent studies, there is evidence of ethical approval by an appropriate body	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of the data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>



Keywords



- Duchenne Muscular Dystrophy
- DMD
- Mental health
- Psychological well-being
- Muscular dystrophy
- Parents' caregivers
- Family burden/care burden



Results: Health Related Quality of Life

$\frac{3}{4}$ of the articles reviewed concluded a decrease in Health-Related Quality of Life among caregivers

Table 1: Health Related Quality of Life					
Study	Setting(s); sample	Method(s) for data collection	Main aspect(s) investigated	Instrument(s)	Findings
Quality of life and informal care burden associated with duchenne muscular dystrophy in Portugal: the COLDUCH study [1]	46 DMD caregivers (8 ambulatory, 38 non-ambulatory patients)	Caregivers to patients with DMD registered through Portuguese	COI, HRQoL, burden of caregivers specifically related to work time missed (absenteeism).	EuroQoL-5D (EQ-5D-3L), WPAI-GH, Wilcoxon and Kruskal-Wallis tests.	The mean reported quality of life for ambulatory patients was significantly higher than for non-ambulatory patients. Caregivers of non-ambulatory patients reported higher burden of care compared to patients without non-ambulatory patients. Problems were faced in self-care, mobility, and activities of daily living. Work impairment of 30.5%.
Quantifying the burden of caregivers in Duchenne muscular dystrophy [4]	Multinational study, 770 caregivers				Approximately half of the caregivers reported being moderately or extremely anxious or depressed ($p < 0.001$ 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 ($p = 0.006$).
Characterizing the quality-of-life impact of Duchenne muscular dystrophy on caregivers a case-control investigation [7]	566 DMD caregivers 594 non DMD comparison caregivers				DMD caregivers reported worse physical health, mental health, positive affect, environmental mastery, stressful life events, and difficulty paying bills than comparison caregivers.
Drivers of caregiver impact in Duchenne muscular dystrophy: a cohort study [9]	566 DMD Caregivers	Eligible participants were age 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.	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	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	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.
Measuring Duchenne muscular dystrophy impact: development of a proxy-reported measure derived from PROMIS item banks [10]	521 DMD caregivers				Caregivers presented with comorbid health conditions, with the most prevalent being back pain, depression, insomnia, and arthritis.
A qualitative study on the impact of caring for an ambulatory individual with nonsense mutation Duchenne muscular dystrophy [12]	10 DMD caregivers				Caregivers reported proximal impacts such as physical, emotional and distal 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.

DMD caregivers reported worse physical health, mental health, positive affect, environmental mastery, stressful life events, and difficulty paying bills than comparison caregivers.⁷

Caregivers presented with comorbid health conditions, with the most prevalent being back pain, depression, insomnia, and arthritis.¹⁰



Results: Psychological Well-being

¾ of the articles reviewed concluded a decrease in Psychological Well-Being among caregivers

Table 2: Psychological Well-being			
Study	Setting(s); sample		Main finding(s)
Quality of life and informal care burden associated with duchenne muscular dystrophy in Portugal: the COLDUCH study [1]	46 DMD caregivers (8 ambulatory, 38 non-ambulatory patients)	Approximately half of the caregivers reported being moderately or extremely anxious or depressed ($p < 0.001$ when compared to general population). ⁴	
Quantifying the burden of caregivers in Duchenne muscular dystrophy [4]	Multinational study, 770 caregivers		
Characterizing the quality-of-life impact of Duchenne muscular dystrophy on caregivers a case-control investigation [7]	566 DMD caregivers 594 non DMD comparison caregivers	Caregivers and a nationally representative comparison group of parents of children without DMD stratified by Child Age Group	DMD caregivers reported worse physical health, mental health, positive affect, environmental mastery, stressful life events, and difficulty paying bills than comparison caregivers.
Drivers of caregiver impact in Duchenne muscular dystrophy: a cohort study [9]	566 DMD Caregivers	Eligible participants were age 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.	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. Caregivers presented with comorbid health conditions, with the most prevalent being back pain, depression, insomnia, and arthritis
Measuring Duchenne muscular dystrophy impact: development of a proxy-reported measure derived from PROMIS item banks [10]	521 DMD caregivers	member caregivers in terms of QOL, life stress, and indirect costs.	
A qualitative study on the impact of caring for an ambulatory individual with nonsense mutation Duchenne muscular dystrophy [12]	10 DMD caregivers	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, 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, USNIH, The	Caregivers reported proximal impacts such as physical, emotional and distal 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.

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.¹²



Results: Financial Burden

5/8 of the articles reviewed concluded an increased Financial Burden among caregivers

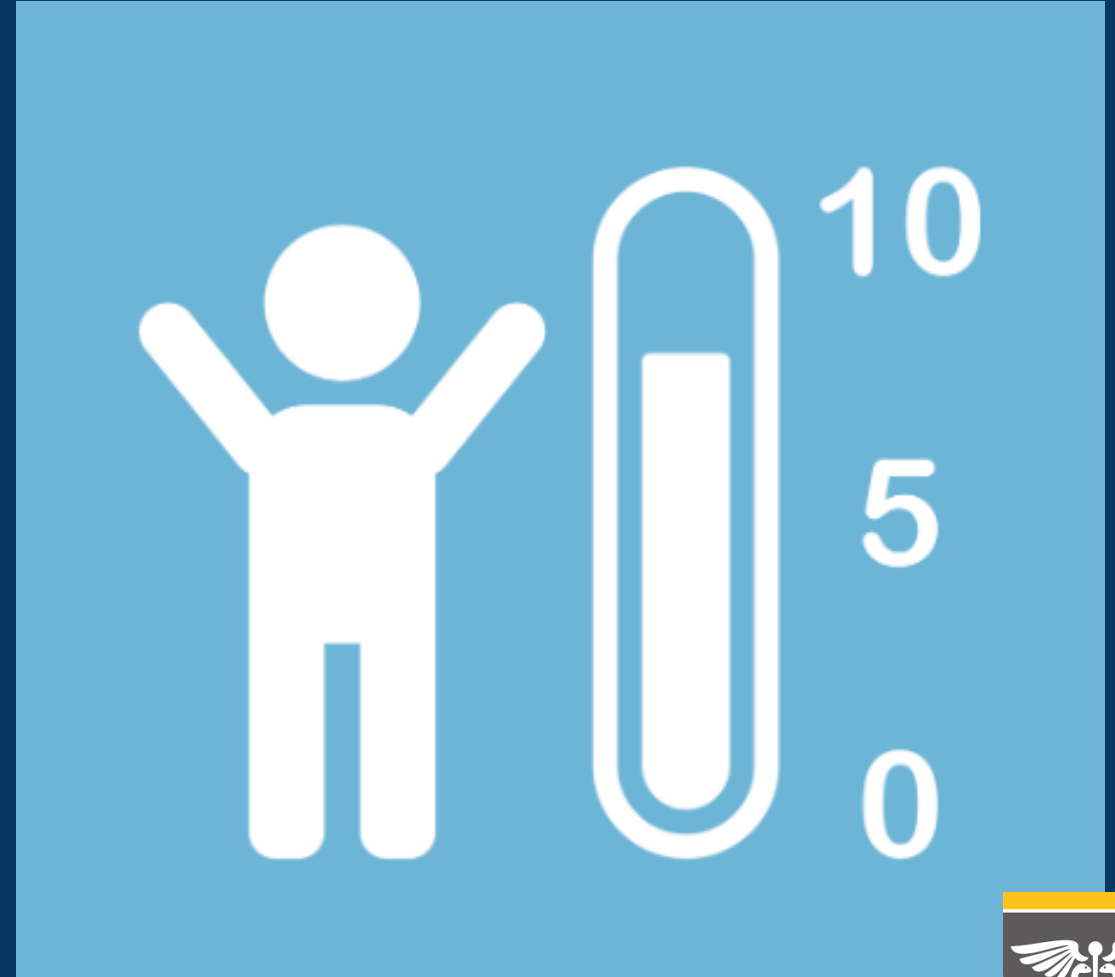
Table 3: Financial Burden					
Study	Setting(s); sample	Method(s) for data collection	Main aspect(s) investigated	Instrument(s)	Main finding(s)
Quantifying the burden of caregivers in Duchenne muscular dystrophy [4]	Multinational study, 770 caregivers	A web-based survey	<p>Nearly 30% of caregivers estimated the annual household cost burden at over \$5,000 (p 0.006).⁴</p>		Approximately half of the caregivers reported being moderately or extremely anxious or depressed (p<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 0.006).
The burden of Duchenne muscular dystrophy [5]	770 patient-caregiver pairs Germany = 173 Italy = 122 United Kingdom = 191 United States = 284				The total society burden was estimated at between \$80,120 and \$120,910 per patient and increased with disease progression. The mean annual household burden was estimated between \$58,440 and \$71,900
Characterizing the quality-of-life impact of Duchenne muscular dystrophy on caregivers a case-control investigation [7]	566 DMD caregivers 594 non DMD comparison caregivers				DMD caregivers reported worse physical health, mental health, positive affect, environmental mastery, stressful life events, and difficulty paying bills than comparison caregivers.
Interplay of disability, caregiver impact, and out-of-pocket expenditures in Duchenne muscular dystrophy: a cohort study [8]	566 DMD Caregivers				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.
Drivers of caregiver impact in Duchenne muscular dystrophy: a cohort study [9]	566 DMD Caregivers				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.

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.⁹



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.



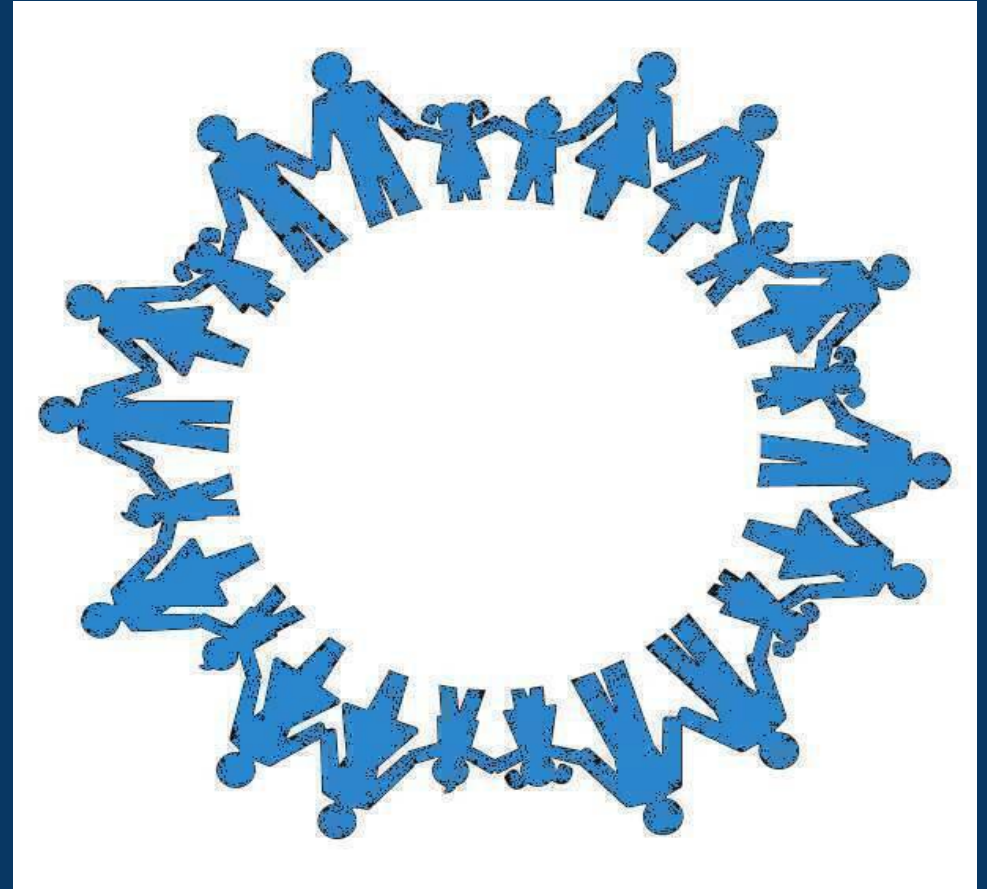
Discussion: Financial Burden

- 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.



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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 Parsamanesh; 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.¹ The physical, mental, and social well-being impacts on 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.

Observation Tables of Health Related Quality of Life, Psychological Well-being, and Financial Burden					
Study	Setting(s): sample	Method(s) for data collection	Main aspect(s) investigated	Instrument(s)	Main findings(s)
Quality of life and informal care burden associated with duchenne muscular dystrophy in Portugal: the COIDUCH study [1]	46 DMD caregivers (8 ambulatory, 38 non-ambulatory patients)	Caregivers to patients with DMD registered through Portuguese Neuromuscular Association; Face-to-face interviews with trained interviewers followed by caregivers answering a customized questionnaire.	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).	EuroQoL-5D (EQ-5D-3L), WPAI-GH, Wilcoxon and Kruskal-Wallis tests.	The mean reported daily activity impairment was 60%. Caregivers of non-ambulatory patients reported a mean daily activity impairment of 68%. Caregivers of non-ambulant 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%.
Quantifying the burden of caregivers in Duchenne muscular dystrophy [4]	Multinational study, 770 caregivers	Caregivers to eligible patients were invited to complete a questionnaire online	To investigate the subjective caregiver burden associated with DMD, prevalence of anxiety and depression, and caregiver health related quality of life	EuroQoL EQ-5D-3L (EQ-5D), a Visual Analogue Scale (VAS), and the SF-12 Health Survey (SF-12)	Approximately half of the caregivers reported being moderately or extremely anxious or depressed (p<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=0.006).
Characterizing the quality-of-life impact of Duchenne muscular dystrophy on caregivers a case-control investigation [7]	566 DMD caregivers and 594 non DMD comparison caregivers	A web-based survey included DMD caregivers and a nationally representative comparison group of parents of children without DMD stratified by Child Age Group	To examine the impact of DMD on family member caregivers in terms of QOL, life stress, and indirect costs.	PROMIS-10 General Health, NeuroQOL Positive Affect and Well-Being, The Ryff Environmental Mastery, and the Centers of Disease Control (CDC) Healthy Days Core Module	DMD caregivers reported worse physical health, mental health, positive affect, environmental mastery, stressful life events, and difficulty paying bills than comparison caregivers.
Drivers of caregiver impact in Duchenne muscular dystrophy: a cohort study [9]	566 DMD Caregivers	Eligible participants were age 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.	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	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, USNH, The CDC Healthy Days Core Module, Current-Reserve-Building Measure, QOL appraisal, and ANOVA	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.
Measuring Duchenne muscular dystrophy impact: development of a proxy-reported measure derived from PROMIS item banks [10]	521 DMD caregivers	Web-based study following telephone interviews as a pretest	Fatigue support, strength impact, cognitive function, upper extremity function, positive affect, negative affect, sleep-device symptoms, and mobility	PROMIS item banks	Caregivers presented with comorbid health conditions, with the most prevalent being back pain, depression, insomnia, and arthritis
A qualitative study on the impact of caring for an ambulatory individual with nonsense mutation Duchenne muscular dystrophy [12]	10 DMD caregivers	Patients with DMD from Germany, Italy, the UK, and the US recruited through national registries. Caregivers invited to complete an online questionnaire.	The impacts and challenges experienced by caregivers of ambulatory individuals before treatment with Ataluren	PAG and MAXQDA	Caregivers reported proximal impacts such as physical, emotional and distal 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.
The burden of Duchenne muscular dystrophy [5]	770 patient-caregiver pairs Germany = 173 Italy= 122 United Kingdom= 191 United States = 284	Eligible patients and one of their caregivers (e. g., parent) were invited to complete a questionnaire online	To estimate the total cost of illness and economic burden of DMD to society and caregiver households.	Health Utilities Index and EuroQoL EQ-5D	The total society burden was estimated at between \$80,120 and \$120,910 per patient and caregiver. The mean annual household burden was estimated between \$68,440 and \$71,900
Interplay of disability, caregiver impact, and out-of-pocket expenditures in Duchenne muscular dystrophy: a cohort study [8]	566 DMD Caregivers	A web-based survey	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	DMD caregiving Impact Measure, PROMIS-derived parent-proxy (PPP), Cohens criteria, Hierarchical cluster analysis, and Latent Profile Analysis	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.

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.¹ As a result, caregivers have 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 monetary value of lost leisure time, and reduced quality of life, estimating at between \$58,440 and \$71,900. Therefore, this terminal illness has many costs to consider and is associated with a significant economic burden.⁵



Future Considerations and Limitations

Further exploration of the function and availability of support programs such as therapy will allow careers 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.

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