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The role of physiotherapy in Muscular Dystrophies: an online survey of physiotherapists

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Abstract

Aim

Muscular Dystrophy (MD) is a chronic**,** life-limiting condition which requires multi-disciplinary care, including physiotherapy. Little is known about physiotherapy services for people with MD (pwMD) in Ireland. The aim was to establish the profile of physiotherapists caring for pwMD, the profile of the pwMD treated, and to identify education or training requirements and current services gaps.

Methods

A survey was developed with stakeholder involvement and distributed via Twitter and email to members of the Irish Society of Chartered Physiotherapists.

Results

Forty-three responses were included in the analysis. Respondents' median years of experience was 12 (IQR=12). The most common work settings were acute public hospitals, 21 (48.8%). The median number of pwMD treated in the past five years was three (IQR=3). The most common focus of treatment was maintenance of mobility 32 (72%), respiratory treatment 23 (53.5%) and aid provision 23 (53.5%). Altogether, respondents reported using thirty-five different outcome measures for pwMD. Almost half, 20 (46.5%) had no undergraduate or postgraduate training in MD. The majority of physiotherapists, 26 (60.5%) felt extra education about MD was needed, with most 36 (83.7%) identifying a gap around education regarding the transition from paediatric to adult services. Over half 22 (54%) felt services for pwMD were inadequate.

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Conclusion
Physiotherapists see pwMD in various settings. Many physiotherapists have received little training in MD and feel further training on the area of MD is required particularly around the transition from paediatric to adult services.

Introduction

Muscular Dystrophy (MD) is a collective term for a group of rare, clinically heterogenous, inherited neuromuscular disorders, with a prevalence of between 19.8 and 25.1 years per 100,000 person years worldwide.[1,2] They are characterised by progressive muscle weakness affecting skeletal muscles while respiratory and cardiac muscles can be affected in the later stages.[2] Different types of MD vary in their age of onset, symptoms, prognosis and rate of progression.[3] The most common types of MD are Myotonic Dystrophy, Duchenne Muscular Dystrophy and Facioscapulohumeral Muscular Dystrophy.[1] No cure exists, but recent advancements in medical care with the use of corticosteroids, implanted cardiac devices, ventilation, rehabilitation as well as orthopaedic surgery have improved outcomes and extended the life expectancy of pwMD.[4-6]

The multi-disciplinary management of MD aims where possible, to prevent disuse atrophy; to maintain and optimize residual muscle strength; to minimize progression of muscle weakness; to support and optimize cardiorespiratory function; to enhance exercise tolerance, energy efficiency, and energy conservation; preserve function, avoid secondary complications, optimise autonomy and quality of life[7]. Physiotherapy can aid in the preservation of motor function, the management of contractures and the maintenance of respiratory function, during all phases including the ambulatory, early non-ambulatory and late non-ambulatory phases.[7,8] The role of muscular exercise for this cohort remains controversial, with some sources recommending concentric sub-maximal resistance exercise and moderate aerobic exercise recommended, but gains are likely to be small.[7,8] A physiotherapy guideline for pwMD recommends stretching, gentle exercise, passive range of motion and respiratory physiotherapy depending on the stage and symptoms, though it is unclear how applicable these are to other forms of MD (9). A consensus statement recommends stretching, orthoses and gentle therapeutic exercise to manage contractures and maintain mobility and quality of life in people with other forms of MD.[7] Access to best practice management for pwMD remains challenging. In the UK, only 55% of pwMD who have a scoliosis met minimum recommendations of attending physiotherapy at least once every six months.[10] The equivalent access to physiotherapy and interventions available to pwMD in Ireland is unknown.

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In the context of the current knowledge gap regarding access to Physiotherapy for pwMD in Ireland three primary aims were identified for this study in conjunction with stakeholders; firstly to investigate the profile of Irish physiotherapists treating pwMD, including their MD specific training and knowledge and educational needs; secondly to profile the pwMD treated by respondents, and finally to explore the views of physiotherapists regarding current services, including transition from paediatric to adult services, and identify gaps in these services.

Methods

As no extant questionnaire existed, a bespoke, online survey was designed to address study aims. This was designed with consultation from stakeholders which included an academic physiotherapist (JB), a clinical physiotherapist with expertise in MD (DMy) and a representative (BM) from Muscular Dystrophy Ireland, a voluntary organisation which provides support services for pwMD and other neuromuscular diseases.[11] Qualtrics[xm] (https://www.qualtrics.com/) was used to generate and distribute the survey[12]. Ethical approval was granted by the Trinity College Dublin School of Medicine Research Ethics Committee.

The survey sought information on physiotherapy treatment, knowledge gaps, limitations of current services, the transition from paediatric to adult services as well as general feedback. A mix of open-ended and closed questions were included.[13] The survey was piloted by eight physiotherapists with a mix of academic and clinical backgrounds, with adjustments made as required.[14]

The final survey consisted of two sections, part one consisted of six basic demographic questions and part two consisted of twelve MD specific questions **(Supplementary File 1)**. It opened on 16.03.22 and was distributed, along with the participant information leaflet via a tweet from the Twitter account of the Discipline of Physiotherapy in Trinity College Dublin with the survey link embedded and was retweeted a week later. Additionally, the survey was distributed to members of the Irish Society of Chartered Physiotherapists via email and was also sent directly to individuals who expressed an interest. The survey remained open until 01.04.22.

Respondents were eligible to partake if they were a qualified physiotherapist, statutory board (CORU) registered, working in the Republic of Ireland and had treated a pwMD in the past five years. Informed consent was stated as part of completion of the survey.

Only surveys with a fully completed data set were included in this study. Data was transferred from Qualtrics to a Microsoft Excel file and to IBM SPSS 26.0 for analysis. Descriptive statistics

were used to summarise respondent's years of experience and number of pwMD treated. Open text responses were grouped categorically.[15] The reporting of this study was guided by the STROBE guidelines.[16]

Results

A total of 52 responses to the survey were received between the 16th - 30th of March 2022, of which 43 were included in the analysis. One respondent did not meet the inclusion criteria and eight were excluded due to missing data.

Profile of physiotherapists

The professional profile of respondents is shown in Table 1. The median number of years worked was 12 (IQR=12), ranging from one to 40. The median number of pwMD treated in the past five years was three (IQR=3) and ranged from one to over 100. The majority, 79.1% (n=34), reported treating five or fewer pwMD. One participant reported seeing over 100 pwMD.

Table 1: Profile of respondents

Demographic information	**Number of respondents (%)**
Working position	
Staff Grade	6 (14.0)
Senior Grade	24 (55.8)
Clinical Specialist	8 (18.6)
Private Practitioner	4 (9.3)
Manager	1 (2.3)
Total	43
Workplace	
Acute Hospital	21 (48.8)
Secondary care	11 (25.6)
Private Practice	3 (7.0)
Nursing Home	1 (2.3)
Other	7 (16.8)
Total	43

Clinical Area	
Musculoskeletal	4 (9.3)
Respiratory	4 (9.3)
Neurology	10 (23.3)
Care of the Elderly	6 (14.0)
Paediatrics	11 (25.6)
General medicine	3 (7.0)
Other	5 (11.6)
Total	43

Profile of MD patients treated

The majority, 55.8% (n=24), of physiotherapists treated adults with MD while 30.2% (n=13) treated children and 14% (n=6) treated both adults and children. More than half (n=23, 53.5%) of respondents treated mainly outpatients, while 18.6% (n=23) treated inpatients and 27.9% (n=12) treated both.

Treatments varied with 115 treatments foci selected by respondents (n=43) (Table 2). Respondents could select more than one treatment focus which were grouped as follows; maintenance of mobility was listed by 72% (n=32), respiratory physiotherapy was listed by 53.5% (n=23) and the provision of aids was listed by 53.5% (n=23).

Table 2: List of Outcome Measures (OCMs) Employed by Respondents (respondents could select>1)

Category (no of OCMS)	Specific OCMs	Frequency
Function (n=9)	1) North Star Ambulatory Assessment	9
	2) Berg Balance Scale	5
	3) 5-Times Sit-to-Stand	5
	4) Timed Up and Go	3
	5) Sit-to-Stand	2
	6) Timed Rise from Supine	2
	7) Rivermead Motor Assessment	1
	8) Gowers Sign	1
	9) Barthel Index	1

Musculoskeletal (n=5)	1) Range of Motion	10
	2) Oxford Scale	6
	3) Manual Muscle Test	5
	4) Grip Strength	4
	5) Postural Assessment	1
Mobility (n=5)	1) Timed Walk Tests (10MWT/6MWT)	16
	2) 10 Meter Shuttle Run Test	2
	3) Timed 4-Stair Climb	2
	4) 3D Gait Analysis	1
	5) Elderly Mobility Scale	1
Respiratory (n=6)	1) Cough Peak Flow	7
	2) Sniff Nasal Inspiratory Pressure	2
	3) Modified Medical Research Council Dyspnoea Scale	1
	4) Total Lung Capacity	1
	5) Spirometry	1
	6) Respiratory Markers e.g. SpO2 and FVC	1
Quality of Life (n=3)	1) EuroQOL-5 Dimension	2
	2) Quality of Life Scale	1
	3) Fatigue Severity Scale	1
Other (n=4)	1) Numerical Rating Pain Scale	1
	2) BORG Rating of Perceived Exertion Scale	1
	3) Physiological Cost Index	1
	4) Physiological Outcomes e.g., CVS/ABGs/CXR	1

10MWT; 10 meter walk test, 6MWT; FVC; forced vital capacity, CVS; cardiovascular system, ABGs; arterial blood gases, CXR; chest x-ray

Outcome measures

Respondents listed 35 distinct outcome measures with the use of >1 outcome measure reported by 25 respondents, while eight (18.6%) reported using none. The majority of measures focused on function (n=29), musculoskeletal symptoms (n=26) and mobility (n=21), while a small number focused on respiratory function (n=13), quality of life (n=4) and pain (n=1) while three fitted other categories (Table 2).

Figure 1 Focus of Physiotherapy Treatments

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Physiotherapist's training and knowledge

The majority, 67.4% (n=29), of respondents did not recall undergraduate training about MD while 60.5% (n=26) reported not having conducted continuous professional development (CPD) on the subject. Almost half (46.5%, n=20) reported neither having received undergraduate training nor conducted CPD in the area of MD, while only 18.6% (n=8) reported having done both.

With regard to awareness of sources of information the majority were aware of Muscular Dystrophy Ireland (62.8%, n=27), less than half (41.9%, n=18) were aware of Muscular Dystrophy UK and 14% (n=6) of respondents were not aware of any sources of information.

Sixty percent of respondents (n=26) identified general educational needs for physiotherapists working in the area of MD. The educational needs identified were divided into six different categories: general management/education about MD (n=21, 48.9%), which featured most prominently; then disease pathophysiology (n=7, 16.3%); the respiratory management of MD (n=5, 11.6%); the assessment of MD; and other (n=1, 2.3%). Eighty-three percent of respondents (n=36) felt that there were additional educational needs for physiotherapists to help manage the transition from paediatric to adult services. The most common problems identified with the transition were poor patient management (n=15, 34.9%) and poor service provision (n=10, 23.3%).

Service needs

Over half of respondents (n=22, 54%), felt that the physiotherapy services in their area did not adequately address the needs of pwMD. The most common factor identified as affecting service provision was inadequate service provision (n=7, 17.1%), followed by lack of

education/training (n=3, 7.3%) and poor links between the acute and community settings (n=3, 7.3%).

Discussion

This is the first study to examine the current role played by physiotherapists in the care for pwMD in Ireland. The aim of this study was to establish the profile of physiotherapists caring for pwMD, the profile of the pwMD treated, and to identify education or training requirements and current services gaps. Our main findings showed that physiotherapists who completed this survey were generally experienced with a median of 12 years of clinical experience. Despite this experience, we identified a low level of clinical exposure to pwMD in the majority of respondents, with a small number of exceptions. We also identified significant training needs particularly around general management of pwMD and a need for improved services for this population.

The reported lack of formal training was an important finding. A significant proportion had not been trained about MD or taken up postgraduate learning opportunities in this area and may be seeing pwMD without any specific formal education. Most respondents were not treating a pwMD every year, highlighting it is a small part of a varied caseload. Considering this, it is not surprising that such a high proportion of respondents felt there were additional educational needs for physiotherapists and identified the current lack of education in the area as a barrier to service provision. Universities should endeavour to cover MD as part of the curriculum. A recorded best practice webinar may be an effective, accessible and convenient way to educate practicing physiotherapists treating pwMD. As a range of different health professionals generally treat pwMD, it is possible that other disciplines may also benefit from additional education in the area.

The diversity of treatment foci outlined in this study indicates that a breadth of physiotherapy techniques are needed in the management of pwMD, including neurological, musculoskeletal and respiratory techniques, likely due to the multi-system complications associated with MD.[7] It is not surprising that respiratory treatment was a common focus as respiratory failure is the most common cause of death in those with MD.[17] Respiratory treatment was a focus for 53.5% (n=23) of respondents and only 9.3% (n=4) worked in a respiratory setting. This may indicate physiotherapists in a variety of clinical areas are dealing with the specific respiratory management demands of MD, although only 11.6% reported needing training in respiratory physiotherapy, so other sources of training and previous exposure to this area may have met this training need.[8] However, although muscular exercises are a common focus, a recent systematic review did not provide evidence of effectiveness for improving overall muscle

strength, although quality of the evidence was low. Notably, this review found evidence, albeit weak, for muscular exercise to improve endurance.[8]

Unsurprisingly, this study highlighted issues about the provision and accessibility of services for pwMD, especially when transitioning from paediatric to adult services. The majority of respondents felt there were concerns around the education of physiotherapists at this time and 23.3% (n=10) specified services were an issue during the transition. The lack of neurological services during the transition period from paediatric to adult services is not unique to Ireland and has been identified as an overlooked need internationally.[18] The transition from paediatric to adult care is likely to become a more prominent issue as pwMD are more likely to live longer into adulthood.[19,20]

The wide variety of outcome measures used was concerning and likely reflects a lack of condition specific knowledge and training. Physiotherapists treating pwMD should endeavour to use validated, reliable and standardised outcome measures to improve clinical decision-making.[21] Core outcome sets for muscular dystrophy are under development as part of the COMET initiative, with the six minute walking test shown to be a potentially useful measure to track the disease course.[22,23] Physiotherapists assessing pwMD should consider incorporating the six minute walk test as part of their assessment test battery and keep up to date with any new outcome measure recommendations as they emerge.

A similar study examining the views of pwMD regarding physiotherapy, exercise and the available services would further expand knowledge regarding these services and requirements for future developments. This is important as pwMD and healthcare providers may differ in the issues they identify.[24]

There were several limitations of this study. Firstly, the number of respondents was low at 52 and the attrition rate of the study was high, as 17.3% (9/52) of those who started the survey did not answer all mandatory questions. This was unexpected due to the brevity of the questionnaire and the reasons for the attrition rate are not clear. Due to the cross-sectional nature of the survey, caution must be applied in the interpretation of results. Despite the survey being anonymous, there is still a risk of social desirability response bias. The stakeholder involvement in the study formation helped create more clinically relevant research questions and useful information[25] and was a notable strength of this study.

This was the first study to examine the role of physiotherapy in treating MD in Ireland. The results suggest physiotherapists generally treat pwMD as part of a mixed caseload in a variety of settings. Most physiotherapists received little or no formal training and a clear training need was identified, which may also be applicable to other health care professionals. Services gaps for pwMD were identified and more focus is needed in particular to manage the transition from paediatric to adult services. Further research should explore if relevant

training in the area of muscular dystrophy maps to content of curricula and investigate the views of pwMD in Ireland on physiotherapy and service requirements.

Declarations of Conflicts of Interest:

None declared.

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Supplementary File 1 - Survey

Demographics

Q1 Please confirm that you are a qualified Physiotherapist (CORU registered or awaiting registration) working in direct patient contact in the Republic of Ireland. If you have answered no, you will exit the survey. Thank you for your time.

- Yes (1)
- No (2)

Skip To: End of Survey If Please confirm that you are a qualified Physiotherapist (CORU registered or awaiting registration... = No

Q2 Please confirm that you have treated at least one patient in the last 5 years with a form of Muscular Dystrophy. If you have answered no, you will exit the survey. Thank you for your time.

- Yes (1)
- No (2)

Skip To: End of Survey If Please confirm that you have treated at least one patient in the last 5 years with a form of Musc... = No

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Q1 How many years have you been working as a Physiotherapist?

_____

Q2 Please indicate which of the following apply to your position.

- Staff Grade (1)
- Senior Grade (2)
- Clinical Specialist (3)
- Private Practitioner (4)
- Other; please specify (5) _____

Q3 Please select the setting that describes your workplace.

- Acute public hospital (1)
- Private hospital (2)
- Primary care centre (3)
- Community hospital (4)
- Private practice (5)
- Nursing home (6)
- Rehabilitation unit (7)
- Hospice (8)
- Other (please specify) (9) _____

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Q4 Please select the clinical area in which you currently work.

- Musculoskeletal Outpatients (1)
- Orthopaedic Inpatients (2)
- Respiratory (3)
- Neurology (4)
- Care of the Elderly (5)
- Paediatrics (6)
- Oncology (7)
- General Medicine (8)
- Cardiology (9)
- Other; please specify (10)

_____

Start of Block: Muscular Dystrophies

Q1 Approximately how many patients with a Muscular Dystrophy have you treated in the last 5 years?

Q2 Were the patients with a Muscular Dystrophy that you treated mainly

- Adults (>18 years) (1)
- Children/Teenagers (18 years) (2)
- Mixture of Adults and Children/Teenagers (3)

Q3 Were the patients with a Muscular Dystrophy that you treated

- Inpatients (1)
- Outpatients (2)
- Mixture of inpatients and outpatients (3)

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Q4 What was the main focus of your Physiotherapy treatment? (tick all that apply)

- Strength training (1)
- Maintaining flexibility (2)
- Maintaining mobility (3)
- Maintaining cardiovascular fitness (4)
- Provision of aids and/or appliances (5)
- Prescription of or referral for orthoses (6)
- Respiratory physiotherapy (7)
- Other; please specify (8) _____

Q5 What outcome measures have you used for your patients with a Muscular Dystrophy?

Q6 Do you recall receiving training on management of Muscular Dystrophies during your undergraduate training?

- Yes (1)
- No (2)

Q7 Which of the following sources of information are you aware of in the area of Muscular Dystrophy?

- Muscular Dystrophies Ireland (1)
- Muscular Dystrophy UK (2)
- Other; please specify (3) _____
- None (4)

Q8 Have you conducted Continuing Professional Development (CPD) in the area of Muscular Dystrophy?

- Yes (1)
- No (2)

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Q9 Have you identified any general educational needs for Physiotherapists working in the area of Muscular Dystrophy?

- Yes (Please Specify) (4) _____
- No (5)

Q10 Do you feel there are any additional educational needs for Physiotherapists working in this area to manage the transition from childhood to adult services for Muscular Dystrophy?

- Yes. Please specify (1) _____
- No (2)

Q11 Do you feel the services in your area adequately address the needs of people with Muscular Dystrophies?

- Yes (1) _____
- No (2) _____
- Unsure (3) _____

Q12 We would very much appreciate any general comments you have relevant to the area of Muscular Dystrophy. Please leave a comment in the box below or else state "no comment".