

Occupational participation and occupational therapy care in Myotonic Dystrophy: A narrative literature review

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Abstract

Myotonic dystrophy, the most prevalent adult-onset muscular dystrophy, is multisystemic, linking progressive neuromuscular impairment and occupational restriction. Both types share myotonia, chronic fatigue, and executive dysfunction with apathy, but differ in weakness distribution and facial involvement. Over 9 years, participation declines in nutrition, fitness, personal care, mobility, community life, and recreation; 47% of DM1 patients do not work, 23% rate daily activities as affected, and 35% and 22% identify fatigue and muscle-locking as important. This review synthesises evidence within the Occupational Therapy Practice Framework: Domain and Process, Fourth Edition (PubMed, Scopus, Google Scholar; English, 2016–2026). Four participation-restriction drivers emerge: distal-to-proximal muscle weakness with grip myotonia; frontotemporal executive dysfunction and apathy; accelerating fatigue and daytime sleepiness; and progressive restrictions in community life, employment, and psychological functioning. 80% of disabled persons live in low- and middle-income countries, where high-income settings report 22 occupational therapists per 10,000. At the same time, 54 World Federation of Occupational Therapists member nations have fewer than one, and ratios as low as 0.001. OT rests on four pillars: COPM-based top-down evaluation; contextual adaptations (wearable ADL effect sizes 1.06 and 1.38; tailored smart-home solutions: 89% ADL improvement, 91% readiness for change at US\$567 per participant; powered-wheelchair intervention transitioning 74.8% of 127 tasks to independent completion); energy conservation through pacing, planning, prioritising, and positioning; caregiver coaching anchored in the OPTIMISTIC trial's DM1-Activ-c endpoint. The disease trajectory is irreversible, but participation restrictions are modifiable; three priorities follow: longitudinal DM-specific outcome studies, DM-specific participation measures more sensitive than impairment tools, and scalable low-cost technology for resource-limited settings.

Keywords: myotonic dystrophy, occupational participation, occupational therapy, assistive technology, caregivers.

Participação ocupacional e cuidados de terapia ocupacional na Distrofia Miotônica: Uma revisão narrativa da literatura

Resumo

A distrofia miotônica, distrofia muscular adulta mais prevalente, é multissistêmica, articulando comprometimento neuromuscular progressivo e restrição ocupacional. Ambos os tipos compartilham miotonia, fadiga crônica e disfunção executiva com apatia, diferindo na distribuição da fraqueza e no envolvimento facial. Ao longo de 9 anos, a participação deteriora-se em nutrição, condicionamento físico, cuidado pessoal, mobilidade, vida comunitária e recreação; 47% dos adultos com DM1 não trabalham, 23% classificam atividades diárias como afetadas, e 35% e 22% identificam fadiga e travamento muscular como importantes. Esta revisão narrativa da literatura sintetiza evidências no Domínio e Processo da Terapia Ocupacional, Quarta Edição (PubMed, Scopus, Google Scholar; inglês, 2016–2026). Quatro direcionadores de restrição à participação emergem: fraqueza muscular distal-proximal com miotonia de preensão; disfunção executiva frontotemporal e apatia; fadiga acelerada e sonolência diurna; e restrição progressiva da vida comunitária, do emprego e do

bem-estar psicológico. 80% das pessoas com deficiência vivem em países de baixa e média renda; contextos de alta renda reportam 22 terapeutas ocupacionais por 10.000 habitantes, enquanto 54 países membros da Federação Mundial de Terapeutas Ocupacionais têm menos de um e proporções tão baixas quanto 0,001. A TO assenta em quatro pilares: avaliação descendente baseada na COPM; adaptações contextuais e tecnologia assistiva — tamanhos de efeito de dispositivos vestíveis em AVDs: 1,06 e 1,38; soluções sob medida de casa inteligente: 89% de melhora em AVDs e 91% de prontidão para mudança a US\$567 por participante; intervenção com cadeira de rodas motorizada transicionando 74,8% de 127 tarefas para conclusão independente; conservação de energia pelos quatro P's (pacing, planejamento, priorização, posicionamento); e orientação de cuidadores ancorada no endpoint DM1-Activ-c do OPTIMISTIC. Embora a trajetória da doença seja irreversível, as restrições à participação dela decorrentes são modificáveis; três prioridades emergem: estudos longitudinais DM-específicos, medidas de participação DM-específicas mais sensíveis que instrumentos de comprometimento, e tecnologia escalável de baixo custo para contextos com recursos limitados.

Palavras-chave: distrofia miotônica, participação ocupacional, terapia ocupacional, tecnologia assistiva, cuidadores.

1. Introduction

Myotonic dystrophy is the most prevalent adult-onset muscular dystrophy, a multisystemic disorder imposing progressive, far-reaching constraints on daily life. Two principal phenotypes exist: myotonic dystrophy type 1 and type 2. Although each phenotype arises from a distinct genetic mechanism, both converge on a shared constellation of neuromuscular, cognitive, and systemic impairments (Group et al., 2019; Yum et al., 2017). DM1 typically presents in a predominantly distal pattern, with severe involvement of the long finger flexors, ankle dorsiflexors and plantar flexors, and the facial and neck musculature, alongside cognitive deficits and a frequently observed affective flattening marked by pronounced apathy (Heugten et al., 2018; LoRusso et al., 2018; Wenninger et al., 2018).

By contrast, DM2 generally presents in a proximal-predominant pattern with muscle pain and stiffness, relative sparing of the facial and bulbar musculature, and a comparatively milder weakness trajectory (LoRusso et al., 2018; Wenninger et al., 2018). Despite these genotypic differences, both phenotypes share myotonia — delayed relaxation of skeletal muscle following voluntary contraction — and profound, debilitating chronic fatigue (LoRusso et al., 2018; Winblad; Lindberg, 2019).

The progressive neuromuscular nature of both DM1 and DM2 is slowly progressive, inherited, and multisystemic, with involvement extending across body functions and structures (Kierkegaard et al., 2017). DM1 is recognised across five clinical forms, from neonatal to late adult onset, and exhibits marked generational anticipation (Group et al., 2019; Yum et al., 2017). Disease-burden enquiry has documented that muscle weakness and fatigue constitute the two most prevalent manifestations of DM1, affecting the vast majority of patients (Landfeldt et al., 2019).

Longitudinal evidence indicates that perceived fatigue and daytime sleepiness both increase significantly over a nine-year interval, correlated with greater muscular impairment, higher body mass index, a history of depression, and psychological distress (Laberge, 2020; Winblad; Lindberg, 2019). Hand myotonia has emerged as a quantifiable, treatment-responsive biomarker in DM1, correlated with key pinch strength, manual dexterity, and fatty replacement within the long finger flexors, with direct implications for engagement in fine-motor occupations (Bulea et al., 2022).

This multisystemic profile operates as an immediate and compounding barrier to occupational participation within the physical, social, and institutional contexts of daily life. The transaction between progressing physical incapacity, slowed hand function, persistent fatigue, and reduced initiative restricts participation across multiple life domains — personal care, mobility, community life, and recreation — with longitudinal work demonstrating significant deterioration over nine years (Raymond et al., 2019). Predictors of such restriction include lower grip strength, higher body mass index, slower stand-and-walk times, use of adapted transportation, and perception of obstacles in the physical environment; most of these predictors are amenable to rehabilitation- and environment-targeted intervention (Raymond et al., 2020).

Central-nervous-system-related symptoms compound these restrictions: apathy, emotional difficulties, and fatigue have emerged as independent risk factors for lower participation, with considerable-to-extreme impact documented across leisure activities, employment, partner relationships, and psychological well-being (Heugten et al., 2018; Landfeldt et al., 2019). The cumulative outcome is frequently characterised as occupational

deprivation, social isolation, and a measurable diminishment of quality of life (Group et al., 2019; Raymond et al., 2019, 2020).

Traditional rehabilitation paradigms, particularly those inherited from biomedical models of disability, have historically adopted a bottom-up approach, organising intervention around the remediation of isolated physiological deficits — muscle strength, joint range of motion, and discrete sensorimotor capacities — on the assumption that remediation would translate into functional recovery. Impairment-focused approaches do not reliably improve engagement in everyday occupation; top-down approaches grounded in occupation have been espoused since the discipline's inception (Wolf et al., 2016).

Contemporary occupational therapy has undergone a substantive paradigm shift, articulated in the Occupational Therapy Practice Framework: Domain and Process, Fourth Edition, which defines the field as the therapeutic use of everyday life occupations with persons, groups, or populations to enhance or enable participation, with services oriented to habilitation, rehabilitation, and the promotion of health and wellness across clients with and without disability-related needs (Association, 2021).

The OTPF-4 Domain delineates five central constructs — occupations (daily life activities in which individuals engage), client factors (capacities and characteristics residing within the person), performance skills (observable actions used to execute tasks), performance patterns (habits, routines, roles, and rituals), and contexts and environments (the physical, social, cultural, temporal, and virtual conditions within which occupation occurs) — while the accompanying Process articulates a recursive cycle of evaluation, collaborative intervention, and outcome monitoring (Association, 2021; Dancza; Rodger, 2018).

Within this frame, the disorder is re-read not as a cluster of bodily deficits awaiting repair but as a dynamic transaction between personal capacities and contextual demands that must be negotiated to sustain participation over time. For individuals living with progressive neuromuscular disease such as DM, the typically irreversible trajectory of degeneration renders the historical objective of restoring lost function largely unattainable and shifts the therapeutic emphasis toward the optimisation of participation within existing constraints (Lambdin-Pattavina; Pyatak, 2022). Recent multidisciplinary consensus on hand function across the wider family of neuromuscular disorders now advocates regular assessment alongside multifaceted management — orthoses, assistive and technological solutions, environmental and task adaptations, exercise recommendations, and advocacy for workplace and educational accommodations — precisely the repertoire of strengths-based, environment-centric strategies that contemporary occupational therapy is positioned to deploy (O'Connell et al., 2024; Renna et al., 2025).

This narrative literature review aims to synthesise contemporary evidence on the occupational challenges encountered by individuals living with myotonic dystrophy and to delineate the evolving role of occupational therapy in promoting participation, safety, and quality of life for this population. By foregrounding strengths-based, environment-centric, and participation-oriented interventions derived from the conceptual scaffolding of the OTPF-4, the review seeks to integrate the dispersed scholarship addressing DM-specific occupational concerns into a coherent account that may guide clinicians, educators, and researchers toward practices better aligned with the lived realities and priorities of those affected by the condition (Renna et al., 2025).

2. Materials and Methods

2.1 Study design

The present review is structured as a narrative literature review, chosen to accommodate the methodological heterogeneity characteristic of scholarship at the intersection of myotonic dystrophy and occupational therapy. Narrative reviews permit the synthesis of evidence drawn from diverse study designs — clinical practice guidelines, observational studies, small-scale intervention reports, and conceptual papers — into a coherent, clinically applicable account. Unlike systematic reviews or meta-analyses, which operate within pre-registered protocols and impose quantitative aggregation, the narrative format foregrounds the explicit articulation of emerging thematic patterns and conceptual transitions across the literature. Accordingly, the present review adheres to established narrative-review conventions rather than to a registered protocol such as PRISMA, prioritising interpretive synthesis over effect-size estimation and statistical pooling.

2.2 Literature search strategy

Literature searches were conducted across four databases: PubMed, Scopus, Web of Science, and Google Scholar. Search strings were adapted to the indexing conventions of each database and combined terms related to myotonic dystrophy, occupational participation, and rehabilitation. Core search terms encompassed 'myotonic dystrophy' together with its phenotypic variants 'myotonic dystrophy type 1', 'myotonic dystrophy type 2', 'DM1', and 'DM2', which were combined with discipline-specific terms including 'occupational therapy', 'occupational participation', 'activities of daily living', 'rehabilitation', and 'neuromuscular disorders'. Boolean combinations such as ('myotonic dystrophy' OR 'DM1' OR 'DM2') AND ('occupational therapy' OR 'occupational participation' OR 'activities of daily living') were deployed to refine the search as appropriate, alongside analogous pairings linking the disease-specific and discipline-specific term groups. Reference lists of relevant reviews and practice guidelines were also hand-searched to identify additional foundational sources. Searches were restricted to records published between 2016 and 2026 and to publications available in English or accompanied by an English abstract, thereby capturing the contemporary evidence base while remaining accessible to monolingual review.

2.3 Study selection

Study selection followed a staged narrative-review process, consistent with narrative-review conventions. First, records identified through the four-database search described above were retrieved. Second, duplicate records retrieved across the databases were removed. Third, the remaining titles and abstracts were screened for relevance to myotonic dystrophy, occupational participation, occupational therapy intervention, or rehabilitation. Fourth, full texts of records passing initial screening were retrieved and examined in detail for conceptual fit with the aims of the review. Fifth, records satisfying all eligibility criteria were included in the qualitative synthesis and organised thematically according to the occupational domains most frequently affected by the disease — self-care and personal care, productivity and employment, leisure and community participation, and the transitions, routines, and contextual conditions that mediate engagement in everyday life. The progression of records through the screening stages is reported descriptively in the present review.

2.4 Eligibility criteria

Inclusion criteria specified peer-reviewed empirical studies, review articles, and clinical practice guidelines addressing myotonic dystrophy (DM1 and/or DM2) in conjunction with occupational therapy, occupational participation, rehabilitation, or related constructs, with sources published primarily between 2016 and 2026 to reflect the contemporary evidence base. Earlier landmark publications were eligible where necessary to support historical or foundational arguments relevant to disease characterisation, the evolution of occupational therapy practice, or the conceptual scaffolding of participation frameworks. Only publications issued in English or accompanied by an English abstract were considered. Exclusion criteria comprised editorials, opinion pieces, commentaries, dissertations and theses, conference abstracts without accompanying full text, grey literature not subjected to peer review, and articles whose substantive content did not address the intersection of myotonic dystrophy and occupational therapy.

2.5 Data synthesis

A thematic synthesis approach was adopted, consistent with established conventions for narrative reviews. Extracted data were grouped thematically according to recurrent topics across the included sources: disease characteristics and clinical presentation of myotonic dystrophy; occupational participation barriers encountered across life domains; intervention approaches deployed within occupational therapy; outcome domains commonly evaluated in the empirical literature; and the conceptual frameworks employed to structure practice, including the Occupational Therapy Practice Framework: Domain and Process, Fourth Edition. Findings were organised into thematic categories and synthesised into a coherent narrative account rather than aggregated quantitatively, thereby preserving the interpretive richness and clinical applicability of the evidence base. No formal risk-of-bias assessment was conducted, as the purpose of the review was conceptual synthesis rather than evidence grading; nevertheless, the search strategy, eligibility criteria, and study selection process were explicitly reported to improve transparency and reproducibility.

2.6 Conceptual framework

The thematic synthesis of the reviewed literature supported the development of a conceptual framework

anchored in the Occupational Therapy Practice Framework: Domain and Process, Fourth Edition, summarising the pathway from myotonic dystrophy to occupational participation and highlighting the contemporary role of occupational therapy in promoting occupational participation for this population. The framework integrates the disease-specific clinical characteristics of DM1 and DM2 — progressive muscle weakness, myotonia, fatigue, cognitive involvement, and multisystem comorbidities — with the five OTPF-4 Domain constructs of occupations, client factors, performance skills, performance patterns, and contexts and environments, illustrating how these elements transact to shape participation outcomes across personal care, productivity, leisure, and community life.

Within this conceptual scaffolding, occupational therapy is positioned as the disciplinary vehicle through which environment-centric, occupation-centred, and strengths-based strategies — orthoses, assistive and technological solutions, environmental and task adaptations, energy-conservation techniques, exercise recommendations, and advocacy for workplace and educational accommodations — are deployed to enable participation where full restoration of bodily function is unattainable. The framework thus provides an organising structure for the synthesis presented in the subsequent sections of this review, linking the multisystemic profile of myotonic dystrophy to the contemporary, participation-oriented repertoire of occupational therapy practice.

Table 1. Principal studies underpinning the present narrative review are grouped by thematic cluster.

Authors, year	Design	Population	Key findings	Relevance to OT narrative
Landfeldt et al. (2019)	Cross-sectional observational (PhenoDM1 cohort, INQoL)	60 adults with DM1 (mean age 45; 45% female)	23% of patients rated daily activities considerably/very much/extremely affected; 47% did not engage in work because of their illness; 35% and 22% rated fatigue and muscle-locking difficulties as considerable/very/extremely important, respectively	Disease-burden anchor— The Impact of Myotonic Dystrophy on Occupational Participation, Social Participation, and Psychological Well-Being
Raymond et al. (2019)	Descriptive longitudinal, 9-year interval	115 adults with DM1 (62% women; mean age 52.3 ± 10.3)	Significant decline over follow-up in nutrition, fitness, personal care, mobility, community life, and recreation; global participation and social activities also declined	Longitudinal participation-restriction evidence — The Impact of Myotonic Dystrophy on Occupational Participation and Caregiver Coaching and Collaborative Practice
Raymond et al. (2020)	Secondary analysis of a 9-year longitudinal design with multiple linear regression	114 adults with DM1 (63.2% women; 78.9% adult onset; mean age 43.5 ± 10.4)	Participation restriction predicted by longer stand-and-walk time, lower grip strength, higher body mass index, use of adapted transportation, and perception of obstacles in the physical environment (adjusted R ² = 0.50)	Predictor-of-restriction anchor— Social Participation and Psychological Well-Being
Laberge (2020)	Prospective cohort, mixed-effects modelling (9-year)	200 (T1) and 115 (T2) adults with DM1	Mean DSS rose from 4.5 (SD 2.9) at T1 to 5.3 (SD 3.4) at T2; mean FSS rose from 4.4 (SD 1.7) to 4.8 (SD 1.7); higher fatigue was associated with female sex, higher BMI, greater muscular impairment, and higher psychological distress	Fatigue-trajectory anchor— Cognitive Effects, Chronic Fatigue, and Routine Management and Energy Conservation and Restructuring of Routines
Okkersen et al. (2018)	Multicentre, single-blind RCT	Severely fatigued adults with DM1	A 10-month individually-tailored CBT programme, optionally combined with graded exercise, improved DM1-Activ-c scores, decreased fatigue, and increased objective physical activity and exercise capacity; falls were more frequent	Core trial evidence — Cognitive Effects, Chronic Fatigue, and Routine Management, Energy Conservation, and Caregiver Coaching
O'Connell et al. (2024)	Multidisciplinary consensus statement	Persons with neuromuscular disorders	Multifaceted management integrating orthoses, assistive and technological solutions, environmental and task adaptations, exercise, medication, surgery, and advocacy for workplace and educational accommodations	Consensus-level hand-function and adaptation anchor— Contextual Adaptations and Assistive Technology and Top-Down Evaluation and Client-Centred Frameworks

Renna et al. (2025)	Systematic review (Cochrane RoB 2 + PEDro)	Adults and children with muscular dystrophy (6 RCTs, 2011–2020)	Occupational therapy centres on adapting daily activities and using compensatory, environment-targeted strategies that involve caregivers; benefits for functional abilities and quality of life are supported; evidence quality is low-to-moderate	Cross-condition OT evidence base — Contextual Adaptations and Assistive Technology, Energy Conservation, and Caregiver Coaching
Wenninger et al. (2018)	Narrative review	DM1 and DM2 phenotypes	Distal weakness involving the long finger flexors, ankle dorsiflexors and plantar flexors, and the facial and neck musculature; bulbar involvement is frequent in DM1; warm-up phenomenon in grip, jaw, and tongue myotonia	Phenotype anchor — Motor Challenges, Myotonia, and Daily Self-Care
Pontes & Polatajko (2016)	Conceptual/theoretical chapter on OT practice frameworks	Occupational-therapy practice settings (client-centred and occupation-based paradigm)	Client-centred, occupation-based practice places the client's occupational goals at the centre of assessment, intervention, and outcomes	COPM-and-client-centred-practice anchor — Top-Down Evaluation and Client-Centred Frameworks
van Heugten et al. (2018)	Cross-sectional cohort	Adults with DM1	Apathy, fatigue, and emotional problems identified as independent risk factors for lower participation; physical and neuropsychological rehabilitation programmes recommended	Cognitive-behavioural predictor of participation — Cognitive Effects, Chronic Fatigue, and Routine Management
Garmendia et al. (2023)	Ecological cross-sectional (virtual-reality assessment)	20 adults with DM1	Planning and level of apathy jointly explained 47.6% of the total variance in LIFE-H daily-functioning scores	Cognitive-behavioural predictor of routine performance — Cognitive Effects, Chronic Fatigue, and Routine Management
Wu et al. (2024)	Comprehensive review (open access)	DM1 and adjacent populations	Cognitive impairment observed in > 50% of DM1 patients, with prominent executive dysfunction affecting planning, organising, initiating, and decision-making	Cognitive-behavioural anchor — Cognitive Effects, Chronic Fatigue, and Routine Management

Source: Authors, 2026.

3. The Impact of Myotonic Dystrophy on Occupational Participation

3.1 Motor challenges, myotonia, and daily self-care

The neuromuscular signature of DM1 — distal-predominant weakness disproportionately involving the long finger flexors, ankle dorsiflexors and plantar flexors, and the facial and neck musculature — constitutes the primary substrate of occupational disruption (LoRusso et al., 2018; Wenninger et al., 2018). Within the adult-onset form, this weakness presents clinically as difficulty executing tasks dependent on fine dexterity of the hands and as foot drop that compromises gait safety (Gourdon; Meola, 2017).

The accompanying phenomenon of myotonia, defined by delayed relaxation of skeletal muscle following voluntary contraction, is observed most prominently as grip myotonia in the fingers, the jaw, and the tongue, and is typically accompanied by a warm-up phenomenon in which repeated contractions transiently improve relaxation (Wenninger et al., 2018). Hand myotonia has been quantified as a treatment-responsive biomarker in DM1, with outcomes from novel portable instrumentation correlated with key pinch strength, manual dexterity test performance, and the degree of fatty replacement observed within MRI of the long finger flexor muscles, thereby linking a measurable physiological parameter to engagement in fine-motor occupations (Bulea et al., 2022).

Beyond the intrinsic muscles of the hand, the facial and bulbar musculature is substantially involved, producing the characteristic "myopathic" or "hatchet" facial appearance, frontal balding, temporal wasting, and ptosis, alongside nasal or slurred speech, dysphagia, and difficulties with chewing, all of which may convey a misleading impression of tiredness, sadness, or emotional indifference to unfamiliar observers (Gourdon; Meola, 2017; Wenninger et al., 2018). Severe weakness of the orbicularis oculi muscles causes not only ptosis but also insufficient eyelid closure, predisposing to recurrent conjunctivitis and further constraining grooming and eye-care occupations (Wenninger et al., 2018). Myotonia extending to the bulbar, tongue, and facial musculature has been documented to interfere directly with talking, chewing, and swallowing, compounding the self-care burden experienced by individuals with DM1 (Gourdon; Meola, 2017).

The functional implications of these combined distal and orofacial manifestations are extensive. Difficulty manipulating fasteners, opening containers, executing grooming tasks requiring sustained grip, and self-feeding through impaired fine motor control has been associated with considerable-to-extreme reductions in the capacity to perform daily activities such as washing, dressing, and housework, as documented within the Individualised Neuromuscular Quality of Life questionnaire (Landfeldt et al., 2019).

More broadly, 23% of adult patients with DM1 rate their ability to perform daily activities as considerably, very much, or extremely affected by the disease; difficulties caused by fatigue and muscle locking were rated as considerable, very, or extremely important by 35% and 22% of patients, respectively (Landfeldt et al., 2019). The cross-sectional PhenoDM1 study also reported that 47% of patients did not engage in work because of their illness (Landfeldt et al., 2019).

3.2 Cognitive effects, chronic fatigue, and routine management

Central-nervous-system involvement is increasingly recognised as a major driver of occupational restriction in DM1. Cognitive impairment has been identified in over half of affected patients, manifesting predominantly as a frontotemporal profile characterised by executive dysfunction — difficulties in planning, organising, initiating tasks, and making decisions (Wu et al., 2024). Recent comprehensive reviews confirm executive dysfunction as the cognitive signature most consequential for routine management, with selective inferiority to healthy controls on prefrontal-functioning tests across adult-onset DM1 and DM2 (Wu et al., 2024).

Fatigue and excessive daytime sleepiness compound these cognitive limitations and disrupt daily schedules synergistically. A 9-year longitudinal investigation documented significant increases in both the mean Daytime Sleepiness Scale score — rising from 4.5 (SD 2.9) at baseline to 5.3 (SD 3.4) at follow-up — and the mean Fatigue Severity Scale score, rising from 4.4 (SD 1.7) to 4.8 (SD 1.7), after adjustment for sex, age, CTG repeat number, habitual bedtime, and other covariates (LaBerge, 2020).

Higher fatigue was associated with female sex, higher body mass index, greater muscular impairment, and higher psychological distress; higher daytime sleepiness was associated with younger age, higher body mass index, greater muscular impairment, psychological distress, and a history of depression (LaBerge, 2020; Winblad; Lindberg, 2019). Perceived fatigue, with both depression-related and muscle-impairment components, is significantly more common in DM1 than in matched healthy controls, underscoring the multidimensional interplay between affective, motor, and central-nervous-system contributors to the fatigue experience (Winblad;

Lindberg, 2019).

Within the occupational domain, executive dysfunction and apathy have emerged as the principal cognitive-behavioural predictors of disrupted routine performance. An ecological assessment employing a virtual-reality executive-function test demonstrated that, although patients did not exhibit major difficulties on global measures, both cold and hot executive functions remained necessary to the correct accomplishment of life habits, with planning and level of apathy jointly accounting for 47.6% of the total variance in daily functioning (Garmendia et al., 2023).

Frontal lobe dysfunction, apathy, and avoidant personality with lack of initiative have been described as occurring independently of fatigue, sleepiness, age, gender, motor disability, and psychopathological domain (Heugten et al., 2018; Wu et al., 2024), reinforcing the status of these central features as direct, separable influences on the attainment of daily-living activities and social interactions. Such apathy has been linked to microstructural change within fronto-subcortical circuits, rather than to affective disturbance alone, underscoring its character as a clinical sign of CNS involvement rather than a secondary motivational symptom (Heugten et al., 2018; Wu et al., 2024).

The cumulative effect is documented in cross-sectional enumeration and longitudinal follow-up. Forty-seven per cent of DM1 patients do not engage in work because of their illness, while longitudinal evidence indicates a progressive 9-year decline in participation across the domains of nutrition, fitness, personal care, mobility, community life, and recreation (Landfeldt et al., 2019; Raymond et al., 2019). Encouragingly, a multicentre randomised trial demonstrated that an individually-tailored 10-month cognitive behavioural therapy programme, optionally combined with graded exercise, produced improvements in capacity for activity and social participation as measured by the DM1-Activ-c score, alongside decreased fatigue and increased objective physical activity and exercise capacity, indicating that fatigue and its cognitive-behavioural drivers constitute modifiable treatment targets amenable to rehabilitation intervention (Okkersen et al., 2018).

3.3 Social participation and psychological well-being

The social and psychological consequences of DM1 are inseparable from the visible, progressive physical changes documented above. Multivariate regression modelling of participation restriction has identified longer stand-and-walk time, lower grip strength, higher body mass index, use of adapted transportation from community services, and perception of obstacles in the physical environment as predictors — most of which are amenable to rehabilitation- and environment-targeted intervention (Raymond et al., 2020).

Daily activities related to mobility and nutrition are typically disrupted early, followed by severe restriction of community participation (Group et al., 2019; Raymond et al., 2019). Longitudinal investigation over a 9-year interval has documented that, although housing, mobility, employment, and recreation were already known to be disrupted, additional domains — nutrition, fitness, personal care, mobility, community life, and recreation — deteriorated significantly within the follow-up period, with global participation and social activities also declining (Raymond et al., 2019).

The facial changes associated with DM1 — temporal wasting, ptosis, hatchet facies, and reduced capacity for facial expression — contribute to the social withdrawal described in qualitative and quantitative accounts. Reduced ability to recognise facial expressions in others, alongside impaired performance on theory-of-mind tasks, has been documented, suggesting that both expressive and receptive social-cognition deficits may accompany the disease and limit engagement in interpersonal exchange (Gourdon; Meola, 2017).

Psychological well-being is similarly compromised. In a cross-sectional survey, the majority of patients with DM1 report feelings of anxiety, worry, depression, frustration, and low confidence or self-esteem to some degree, with women more likely than men to report depressive feelings, and 25% of patients indicating that their appearance was considerably, very much, or extremely affected by the disease (Landfeldt et al., 2019). The cumulative outcome is frequently characterised as occupational deprivation, social isolation, and a measurable diminishment of quality of life, encompassing considerable-to-extreme impact on leisure activities, employment, partner relationships, and psychological well-being (Landfeldt et al., 2019).

Multidisciplinary consensus on hand function across the wider family of neuromuscular disorders correspondingly advocates regular assessment alongside multifaceted management incorporating orthoses, assistive and technological solutions, environmental and task adaptations, exercise recommendations, and advocacy for workplace, educational, and community accommodations, recognising that participation restriction in DM1 is multifactorial in aetiology and largely modifiable in component (O'Connell et al., 2024).

4. Contemporary Occupational Therapy Management

4.1 Top-down evaluation and client-centred frameworks

Contemporary occupational therapy for DM is anchored in the discipline's progressive shift away from bottom-up, impairment-focused assessment toward top-down, occupation-centred evaluation, structured by the Occupational Therapy Practice Framework: Domain and Process, Fourth Edition and its five Domain constructs — occupations, client factors, performance skills, performance patterns, and contexts and environments — which provide the analytic scaffolding within which impairment data are subsequently interpreted (Association, 2021; Dancza; Rodger, 2018).

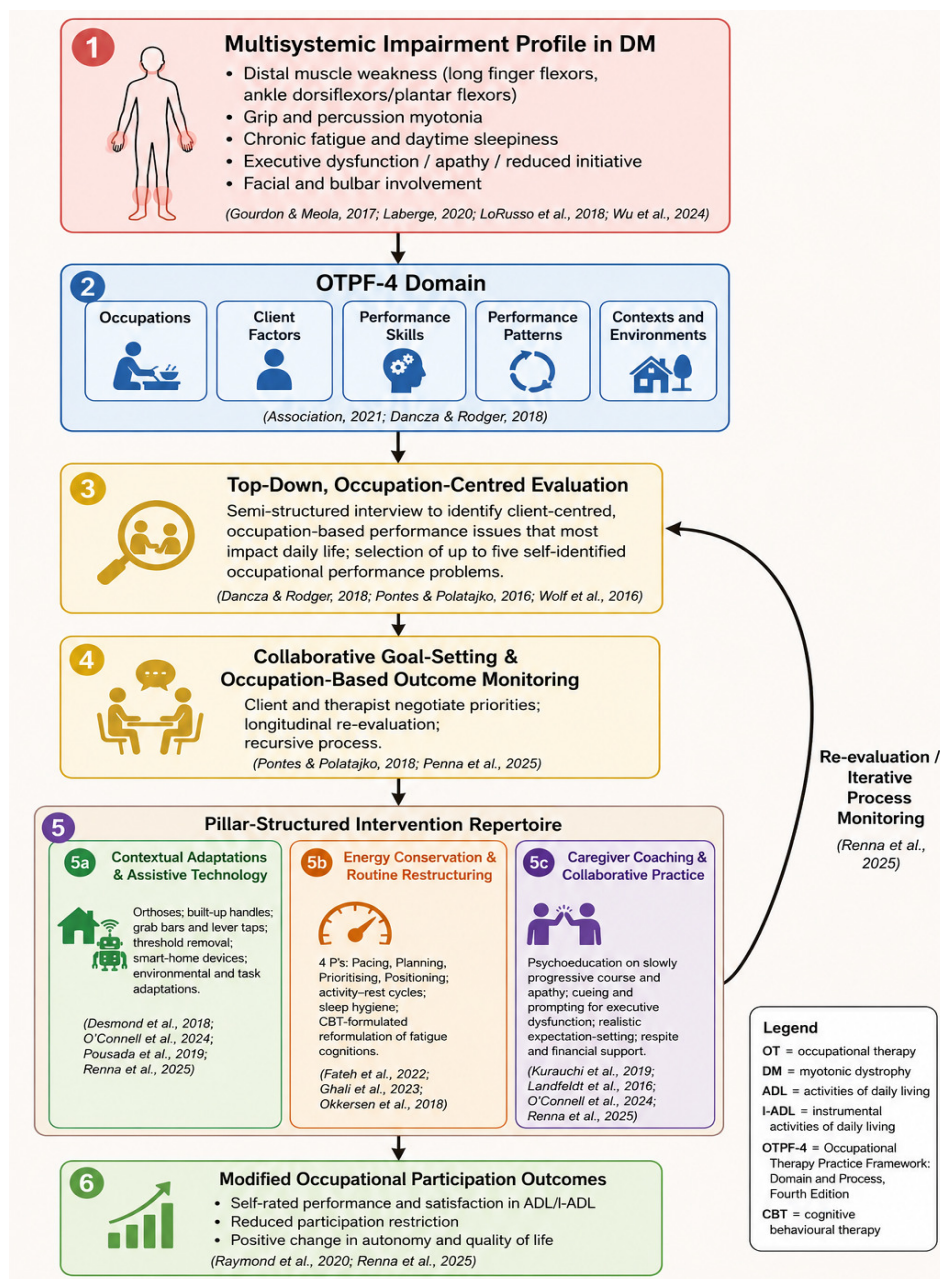


Figure 1. Top-down occupational therapy process applied to myotonic dystrophy. Multisystemic DM impairments are interpreted through the OTPF-4 Domain via top-down, occupation-centred evaluation and client-centred goal-setting. Source: Authors, 2026.

Within this paradigm, the Canadian Occupational Performance Measure is positioned as the principal instrument for goal-setting and outcome monitoring. Its semi-structured interview elicits — within the self-care, productivity, and leisure domains — up to five occupational performance problems chosen by the client, and yields 10-point performance and satisfaction ratings that supply an occupation-anchored complement to the discrete impairment measures traditionally privileged in neuromuscular rehabilitation (O'Connell et al., 2024; Pontes; Polatajko, 2016). Psychometric investigation has documented COPM area-under-curve values of 0.79–0.85 for the detection of clinically meaningful change, with significant longitudinal correlations with the Impact on Participation and Autonomy questionnaire, substantiating the instrument's downstream link to participation outcomes rather than to impairment metrics alone.

By contrast, isolated impairment-level measures such as grip strength have been documented to decline independently of — and at a magnitude exceeding — self-rated participation gains, with longitudinal descriptive work recording significant losses in grip, pinch, and gross and fine dexterity over a 9-year interval; these metrics are accordingly repurposed within contemporary occupational therapy practice as prognostic indicators rather than as principal outcomes in DM (Raymond et al., 2017; Renna et al., 2025).

The translation of client-centred goal-setting into measurable participation gains in DM is empirically substantiated by Aldehag-style hand-training pilots, where intention-to-treat analyses detected significant intervention effects on COPM performance ($p = 0.047$) and satisfaction ($p = 0.027$) subscales alongside a parallel effect on isometric wrist flexor force ($p = 0.048$).

The investigators interpreted these findings as evidence that, in DM1, improvement in engagement with — and satisfaction regarding — self-chosen occupational problems can accompany motor gains, an integration consonant with the introspection that top-down approaches grounded in occupation have been espoused since the discipline's inception, with recent scholarship positioning client-centred, occupation-based practice as the contemporary paradigm and advocating its integration into occupational therapy assessment, intervention, and outcome (O'Connell et al., 2024; Pontes; Polatajko, 2016; Wolf et al., 2016).

4.2 Contextual adaptations and assistive technology

Recent multidisciplinary consensus on hand function across neuromuscular disorders advocates multifaceted management integrating orthoses, assistive and technological solutions, environmental and task adaptations, and advocacy for workplace, educational, and community accommodations — the repertoire of strengths-based, environment-centric strategies that contemporary occupational therapy is positioned to orchestrate (O'Connell et al., 2024). Within the home environment, the practitioner commonly prescribes grab bars in bathing and toileting zones, lever-style door handles and tap fittings, ramp or threshold removal for foot-drop-related gait safety, ergonomic seating supportive of trunk and head posture, and lighting and clutter-reduction strategies designed to compensate for slowed hand function, reduced initiative, and impaired fine manual dexterity (O'Connell et al., 2024; Pousada et al., 2019).

Built-up handles, lightweight cookware, adaptive utensils, button hooks, dressing sticks, and elasticised laces are routinely combined into personalised grooming and kitchen kits designed to bypass long finger flexor and grip myotonia (Landfeldt et al., 2019; O'Connell et al., 2024). Custom resting and functional splints for the wrist and hand are likewise prescribed to address grip myotonia, maintain joint range, and prolong tolerance for sustained fine-motor occupations in dressing, grooming, and self-feeding (O'Connell et al., 2024).

Smart-home technology extends this compensatory, environment-targeted repertoire. Voice-activated assistants, automated lighting, fall-detection sensors, and scheduling or medication reminders have been reported within mainstream-smart-home intervention programmes to enhance occupational and task performance and psychosocial well-being among adults with physical disabilities, with one pilot occupational-therapy-led initiative pairing low-cost smart devices with traditional home modifications recording 89% ADL improvement and a 91% increase in readiness for change at an average cost of US\$567 per participant, and a separate time-limited occupational-therapy-led demonstration recording transitions from assistance-requiring to independent task completion in 74.8% of 127 addressed tasks across powered-wheelchair users (Ding et al., 2025; Fried et al., 2025; Mun, 2025).

A recent systematic review of occupational therapy intervention in muscular dystrophy confirms that adaptation of daily activities and the use of compensatory, environment-targeted strategies — frequently involving caregivers to promote patient independence — constitute the predominant evidence base in this family of

conditions, with a separate meta-analysis of wearable upper-limb assistive devices reporting an overall effect size of 1.06 and a self-perceived effect size of 1.38 for ADL performance across neuromuscular populations (Gandolla et al., 2020; Renna et al., 2025). Throughout such prescription, the framework-level anchor remains the OTPF-4 'contexts and environments' construct, consonant with consensus statements that assistive technology is best conceived as an interface between the person and the life they would like to lead (Association, 2021; Desmond et al., 2018).

4.3 Energy conservation and restructuring of routines

Profound and accelerating fatigue and daytime sleepiness in DM1, compounded by executive dysfunction and apathy, drive reliance on energy conservation and routine restructuring as principal occupational therapy interventions. Longitudinal prospective evidence documents significant 9-year mean increases in both the Daytime Sleepiness Scale (from 4.5 [SD 2.9] to 5.3 [SD 3.4]) and the Fatigue Severity Scale (from 4.4 [SD 1.7] to 4.8 [SD 1.7]), with both trajectories correlated with greater muscular impairment, higher body mass index, history of depression, and psychological distress (Laberge, 2020; Winblad; Lindberg, 2019). Case-control evidence indicates that perceived fatigue in DM1 incorporates both muscle-impairment and depression-related components and is significantly more common than in matched healthy controls, mandating a fatigue-management response that addresses multidimensional contributors rather than muscular exertion alone (Winblad; Lindberg, 2019).

The practitioner operationalises this response through a structured repertoire — the four P's of pacing, planning, prioritising, and positioning — delivered via diary-supported self-monitoring, activity-rest cycles, and the explicit distribution of high-demand occupations across periods of peak energy (Carlo et al., 2020; Fateh et al., 2022). Pacing is articulated as alternating activity and rest, slowing rather than rushing task execution, scheduling deliberate rest periods, and avoiding the accumulation of demanding occupations on the same day; planning involves anticipating and pre-organising the materials, tools, and sequences of daily activity; prioritising encourages categorisation of occupations into essential, deferrable, and delegable categories along with task delegation and simplification; and positioning involves adoption of seated postures for energy-intensive occupations, energy-efficient body mechanics, and frequent-access arrangement of household items (Carlo et al., 2020; Ghali et al., 2023).

Energy diaries and activity checklists are routinely introduced to enable clients to visualise patterns of post-exertional fatigue and to align productive, self-care, and leisure occupations around periods of peak energy, complemented by sleep-hygiene instruction and reformulation of fatigue-catastrophising cognitions where indicated (Bharati; Sahu, 2021; Drummond et al., 2021; Okkersen et al., 2018). The empirical anchor for this intervention is provided by the multicentre OPTIMISTIC randomised trial, in which an individually-tailored 10-month cognitive behavioural therapy programme optionally combined with graded exercise produced improvements in capacity for activity and in social participation as measured by the DM1-Activ-c, alongside decreased fatigue and increased objective physical activity and exercise capacity, demonstrating that fatigue and its cognitive-behavioural drivers constitute modifiable rehabilitation treatment targets (Okkersen et al., 2018).

4.4 Caregiver coaching and collaborative practice

Contemporary occupational therapy practice positions the family not as a peripheral recipient of instruction but as a collaborative partner whose sustained engagement shapes participation outcomes across the disease course. Caregiver burden in DM1 has been documented as substantial and present even when patients are relatively well-functioning, with disagreement between patient and caregiver on the psychological state of the affected individual highlighting the need for facilitated communication, joint problem-solving, and explicit support for the caregiver's psychological health (Kurauchi et al., 2019).

The 9-year longitudinal trajectory further indicates that, for both patient and family, participation in daily and social activities deteriorates significantly over the follow-up interval, with new disruptions in nutrition, fitness, personal care, mobility, community life, and recreation requiring ongoing adjustment of role allocation and support (Raymond et al., 2019, 2020).

The intervention repertoire accordingly encompasses psychoeducation about the slowly progressive trajectory of DM, fluctuating symptom severity, and the cognitive-behavioural features — notably apathy, with its fronto-subcortical basis — that may otherwise be misread as motivational deficit, alongside training in safe physical-handling techniques adapted to the profound distal weakness and fatigability of the patient (Gourdon;

Meola, 2017; Heugten et al., 2018; O'Connell et al., 2024).

Caregivers are coached in cueing and prompting strategies for executive-dysfunction-related routines — diaries, mobile-phone alarms, and scheduled activity cues — and are taught realistic expectations of the patient's residual capability to minimise both overprotection and under-support (Kurauchi et al., 2019; Okkersen et al., 2018). Joint problem-solving around role reallocation, advocacy for respite services and community resources, and explicit inclusion of the caregiver in COPM-style goal-setting permit a shared negotiation of priorities that distributes rather than concentrates burden (Domaradzki; Walkowiak, 2024; O'Connell et al., 2024). In the OPTIMISTIC modular framework, an entire intervention module was dedicated to optimisation of caregiver interaction, including expectation-setting, training in cueing self-reliant behaviour, and protection of the caregiver's own time — offering practitioner-translatable guidance for sustained collaborative practice (Kurauchi et al., 2019; Okkersen et al., 2018).

The literature on caregiver burden in progressive neuromuscular disease broadly supports this direction, demonstrating that adequate support, respite care, and active-coping interventions alleviate subjective burden and improve mental health, particularly when hours of informal care are reduced and financial support is mobilised (Domaradzki; Walkowiak, 2024; Landfeldt et al., 2016). A recent systematic review of occupational therapy in muscular dystrophy corroborates that intervention characteristically involves caregivers to promote patient independence and quality of life, integrating caregiver coaching as a contemporary occupational therapy pillar rather than as an adjunct to direct patient work (Renna et al., 2025).

Table 2. Comparison of the four contemporary OT intervention pillars applied to Myotonic Dystrophy, summarising clinical aim, representative intervention strategies, instruments and outcome measures used in the DM population (or in adjacent neuromuscular populations where DM-specific data are absent).

Pillar/focus	Clinical aim	Representative OT strategies	Instruments and outcome measures used in the DM population
1. Top-down evaluation and client-centred frameworks	Establish an occupation-centred baseline anchored in client-identified priorities, translating impairment data into participation gains	COPM interview eliciting up to five occupational performance problems across self-care, productivity, and leisure; client-led goal-setting; impairment-level measures (grip, pinch, dexterity, myotonia) used as prognostic indicators	COPM (10-point performance and satisfaction scales); Grippit® and Microfet2™; Purdue Pegboard; Assessment of Motor and Process Skills; DM1-Activ-c; Impact on Participation and Autonomy; responsiveness battery (mobility, balance, strength, dexterity)
2. Contextual adaptations and assistive technology	Compensate distal weakness, grip myotonia, foot drop, and visual-cognitive limitations across home, work, and community settings	Grab bars; lever handles and tap fittings; ramps or threshold removal for foot-drop safety; ergonomic seating and lighting; built-up handles, lightweight cookware, adaptive utensils, button hooks, dressing sticks, elasticised laces; resting and functional hand/wrist splints; voice-activated assistants, automated lighting, fall-detection sensors, scheduling/medication reminders; smart-home solutions; wearable upper-limb assistive devices; advocacy for workplace, educational and community accommodations	COPM; Goal Attainment Scale; Functional Independence Measure; ASSIST Functional Performance Index; self-perceived ADL scales; Disability Impact Profile; smart-home outcome battery

3. Energy conservation and restructuring of routines	Mitigate the combined impact of chronic fatigue, daytime sleepiness, executive dysfunction and apathy on daily-schedule execution via pacing, planning, prioritising, and positioning	Energy diaries and activity checklists; structured application of the four P's — pacing (alternating activity and rest), planning (pre-organising tools and sequences), prioritising (essential/deferrable/delegable taxonomy), and positioning (seated work, frequent-access storage, energy-efficient body mechanics); sleep-wake regulation and sleep-hygiene; reformulation of fatigue-catastrophising cognitions	Fatigue Severity Scale; Daytime Sleepiness Scale; DM1-Activ-c; COPM; sleep-wake diaries; Jacobsen Fatigue Catastrophising Scale; self-efficacy and SF-36 scales
4. Caregiver coaching and collaborative practice	Position the caregiver as a collaborative partner to sustain patient participation and distribute, rather than concentrate, caregiver burden	Psychoeducation on DM trajectory, fluctuating symptom severity, and fronto-subcortical basis of apathy; safe physical-handling training adapted to distal weakness and fatigability; cueing and prompting (diaries, mobile-phone alarms, activity cues) for executive-dysfunction routines; expectation-setting avoiding over-protection and under-support; joint problem-solving on role reallocation; advocacy for respite, financial support, and community resources; caregiver inclusion in COPM goal-setting and the OPTIMISTIC caregiver-interaction module	Caregiver Strain Index; Marital Satisfaction VAS; Social Support Inventory – Discrepancy; Apathy Evaluation Scale; Zarit Burden Interview; COPM

Source: Authors, 2026.

5. Discussion

5.1 Integrative synthesis across impairments, environments, and participation

The evidence synthesised within this review (the principal studies underpinning the present synthesis are grouped in Table 1) demonstrates that contemporary occupational therapy functions as a vital bridge between the progressive physical and cognitive decline characteristic of myotonic dystrophy and the preservation of occupational participation. While the multisystemic nature of DM1 and DM2 involves a typically irreversible trajectory of distal-to-proximal muscle weakness, myotonia, and profound fatigue, the paradigm shift toward top-down, participation-oriented intervention ensures that clinical focus remains on the optimisation of autonomy within these constraints (Kierkegaard et al., 2017; Lambdin-Pattavina; Pyatak, 2022). By employing the conceptual scaffolding of the OTPF-4, practitioners move beyond the remediation of isolated physiological deficits. They address the dynamic transaction between the person's residual capacities and the demands of their physical and social environments (Association, 2021; Dancza; Rodger, 2018).

The integration of the four intervention pillars — top-down evaluation, contextual adaptations, energy conservation, and caregiver coaching (the four pillars are compared with respect to focus, instruments, strategies, and outcomes in Table 2) — directly addresses the complex barriers identified in the literature. The use of the COPM ensures that intervention is anchored in self-identified priorities, effectively translating motor gains or compensatory strategies into measurable improvements in satisfaction and performance in activities of daily living (O'Connell et al., 2024; Pontes; Polatajko, 2016).

This is particularly critical given the nine-year longitudinal evidence showing a significant decline in domains such as personal care, nutrition, and community life (Raymond et al., 2019). Contextual adaptations and assistive technology provide the necessary interface between person and environment to bypass physical limitations — grip myotonia and foot drop — and thereby sustain independence in grooming, mobility, and household management (Desmond et al., 2018; O'Connell et al., 2024).

Energy conservation and routine restructuring mitigate the synergistic impact of chronic fatigue and executive dysfunction, enabling individuals to navigate daily schedules despite central-nervous-system involvement (Laberge, 2020; Wu et al., 2024). Caregiver coaching addresses the substantial burden and psychological strain

inherent in managing a progressive neuromuscular condition, fostering a supportive social context for sustained participation (Domaradzki; Walkowiak, 2024; Kurauchi et al., 2019; Landfeldt et al., 2016).

5.2 Global disparities and contingent reach of evidence-based occupational therapy

However, the clinical reach of these participation-oriented interventions is fundamentally constrained by global disparities in the availability of community occupational therapy services. Approximately 80% of individuals with disabilities reside in low- and middle-income countries, where access to rehabilitation is documented as highly variable, poorly measured, and generally low (Abebe et al., 2024; Bright et al., 2018). Significant workforce inequities persist: while some high-income countries report up to 22 occupational therapists per 10,000 population, 54 nations belonging to the World Federation of Occupational Therapists report fewer than one therapist per 10,000, with some LMIC ratios as low as 0.001 (Bhattacharjya et al., 2023; Jesus et al., 2024).

Even within HICs, urban–rural disparities complicate service delivery; longitudinal data from Norway suggest that new community positions are often established in medium-sized municipalities that are already served, failing to level out geographical distributions for rural populations (Maass et al., 2021). Furthermore, in many LMICs, the absence of entry-level education programmes and professional regulation severely limits the development of a competent workforce capable of delivering DM-specific care (Bhattacharjya et al., 2023; Jesus et al., 2024).

These global differences suggest that, while the evidence-based strategies described in this review are effective, their implementation remains contingent upon healthcare-system structures and geographical location — potentially leaving underserved populations in LMICs and rural regions without the specialised support required to navigate the progressive decline of myotonic dystrophy (Abebe et al., 2024; Hayes et al., 2022; Ned et al., 2020).

6. Limitations

6.1 Synthesis methodology and source heterogeneity

The present review adopts narrative synthesis rather than a protocol-driven systematic review with prospective registration, exhaustive multi-database PRISMA-style reporting, dual independent screening, and formal risk-of-bias grading. Reproducibility of the literature yield, formal quality appraisal of individual sources, and quantitative pooling of intervention effects are therefore constrained. The underlying evidence spans heterogeneous source types — clinical practice guidelines, observational cohort studies, small pilot intervention reports, scoping reviews, and conceptual papers — within a broader rehabilitation literature in which the diversity of instruments used to measure access and disability has been documented to limit cross-study comparability (Bright et al., 2018). Such heterogeneity restricts the strength with which qualitative findings can be transferred across the included source types.

6.2 DM-specific samples, outcomes, and design constraints

The DM-specific OT intervention literature remains limited in volume and is frequently confined to small pilot samples. The longest available natural-history study followed 115 participants with DM1 over a nine-year interval (Raymond et al., 2019), and hand-function intervention reports across the broader NMD spectrum are typically restricted to similarly small evaluated cohorts (O’Connell et al., 2024). Outcome measurement draws primarily on instruments developed for broader neuromuscular populations rather than on DM-specific, psychometrically validated tools (O’Connell et al., 2024), with responsiveness data from existing performance-based measures in DM1 underscoring the need for attention to instrument selection rather than reliance on a single dominant outcome (Kierkegaard et al., 2017).

The bulk of the available evidence is observational and cross-sectional; where longitudinal designs do exist — including the nine-year DM1 participation trajectory study (Raymond et al., 2019) and prospectively followed DM1 cohort analyses of daytime sleepiness and fatigue (Laberge, 2020) — they describe natural-history course rather than the effects of specific OT interventions, and accordingly permit only cautious claims about OT impact.

6.3 Geographic concentration and contextual generalisability

The synthesised evidence is geographically concentrated in high-income settings, with limited LMIC and rural representation. Approximately 80% of individuals with disabilities globally live in LMICs (Abebe et al., 2024; Bright et al., 2018), yet across 54 World Federation of Occupational Therapists member nations, the OT workforce comprises fewer than one therapist per 10,000 population, with some LMIC ratios as low as 0.001 (Bhattacharjya et al., 2023; Jesus et al., 2024). Even within HICs, urban–rural inequities persist: in Norway, newly established community OT positions have largely appeared in medium-sized municipalities that already had OT coverage, without levelling out rural distributions (Maass et al., 2021). South African data show that 74.8% of occupational therapists deployed in the private sector serve merely 16% of the country's population (Bhattacharjya et al., 2023). These workforce patterns indicate that DM-specific OT evidence generated in HIC tertiary settings cannot be directly extrapolated to LMIC or non-urban contexts (Abebe et al., 2024; Hayes et al., 2022; Ned et al., 2020).

6.4 Evolution of participation frameworks

The conceptual apparatus underpinning participation-oriented OT intervention has evolved over the review period, transitioning from earlier disability-creation frameworks toward the Occupational Therapy Practice Framework (Association, 2021), within the broader evolution of top-down, occupation-centred reasoning over its bottom-up antecedents (Dancza; Rodger, 2018). This conceptual evolution, while conceptually progressive, complicates longitudinal comparison of participation constructs anchored in different framework generations and limits the comparability of operationalisations of "participation" across the published evidence base.

7. Conclusions

Occupational therapy plays a vital and increasingly central role in preserving the autonomy, dignity, and quality of life of individuals living with myotonic dystrophy. By aligning clinical practice with the participation-oriented thrust of the OTPF-4, the profession provides a comprehensive framework for managing the complex interplay of motor weakness, myotonia, fatigue, and cognitive dysfunction. The evidence presented underscores two points. First, while the underlying disease trajectory is progressive, the resultant participation restrictions are largely modifiable through client-centred goal-setting, environmental adaptation, and the strategic restructuring of daily routines. Second, occupational therapy interventions not only support the individual in maintaining independence but also alleviate the multifaceted burden placed on caregivers — ensuring a more sustainable support system across the lifespan.

To strengthen the evidence base and improve global service reach, more longitudinal studies that track occupational therapy intervention outcomes, participation trajectories, and caregiver burden over extended periods are clearly required. Future research should prioritise the development of DM-specific outcome measures and investigate the scalability of low-cost, technology-driven solutions to address the documented disparities in access between high-income and low-income settings. Sustained inquiry into the long-term impact of participation-oriented care is essential to ensuring that individuals with myotonic dystrophy can continue to lead meaningful and engaged lives despite the challenges of their condition.

8. Authors' Contributions

Zazogkas Zisis: conceptualization, methodology, investigation, literature search, formal analysis (thematic synthesis), writing - original draft, visualization, and project administration. *Vlotinou Pinelopi*: conceptualization, methodology, supervision, validation, and writing - review and editing. All authors reviewed and approved the final version of the manuscript.

9. Conflicts of Interest

No conflicts of interest.

10. Ethics Approval

Not applicable.

11. Artificial Intelligence Statement: Declaration of Generative AI and AI-Assisted Technologies in the Writing Process

During revision, generative AI-assisted tools (OpenAI ChatGPT, 2026) were used only for language editing, formatting support, and editorial refinement of wording. These tools were not used to generate scientific data, conduct independent evidence appraisal, or make autonomous interpretations. The Graphical Abstract was created entirely by the authors and was not generated or assisted by artificial intelligence. All AI-assisted content was reviewed, verified, and approved by the authors, who take full responsibility for the accuracy, integrity, and final content of the manuscript.

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