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SPECIAL ARTICLE

Improving psychosocial and digital care pathways for Duchenne muscular dystrophy: insights from the Duchenne Switzerland Conference 2025

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Summary

Duchenne muscular dystrophy (DMD) is a rare neuromuscular disease, affecting approximately 1 in 3,500 to 5,000 live male births worldwide. Despite medical advances, families continue to face considerable challenges in navigating fragmented health and social care systems, coping with long-term uncertainty, and accessing timely psychosocial and digital support.

This viewpoint summarises key themes, identifies knowledge transfer strategies, and proposes future directions for optimising DMD care in Switzerland and internationally. It reflects the growing recognition that successful care for rare diseases such as DMD must centre families and follow a holistic approach that combines excellent clinical care with digital innovation and psychosocial support frameworks.

Our conclusions are drawn from the Duchenne Switzerland Conference 2025, held on 26 September at the Swiss Paraplegic Centre in Nottwil, Switzerland, a unique forum for interdisciplinary exchange between families, clinicians, therapists, researchers, and patient organisations involved in the care and support of individuals with DMD. With over 120 participants and a fully multilingual setup, the conference highlighted current care challenges, psychosocial needs across the DMD care continuum, and emerging digital health solutions.

The programme included keynote lectures and parallel sessions covering topics such as digital platforms and patient journey tools, assistive technologies, participation and empowerment, mental health, care management, and community-based care. Evidence from international and national research projects, including data from the Care-NMD-CH project, underscored regional disparities and systemic gaps in service provision. The role of coordinated care networks such as Myosuisse and Swiss-Reg-NMD was also discussed in the context of citizen science and participatory research and care approaches.

Workshops and presentations showcased examples of inclusive technologies and participatory health communication, including AI-assisted translation and digital tools to enhance daily autonomy and engagement for individuals with DMD. Sessions on mental health and resilience highlighted the ongoing emotional and psychological strain on families, emphasising the need for sustainable psychosocial interventions as part of integrated care.

Introduction

Duchenne muscular dystrophy (DMD) is a rare progressive neuromuscular disorder that profoundly impacts the physical, emotional, and social dimensions of patients and their families [1]. DMD is caused by mutations in the dystrophin gene, leading to muscle degeneration and associated comorbidities such as cardiac and respiratory dysfunction [2]. The clinical trajectory of DMD is characterised by many challenges, including a decline in functional abilities, which complicates man-

agement and requires a comprehensive, multidisciplinary approach to care [3, 4]. As treatment options continue to evolve, emerging evidence emphasises the critical importance of personalised care strategies that address both the physical aspects of the disease as well as the psychosocial challenges faced by patients and their families [5, 6]. For example, caregivers of individuals with DMD experience a considerable burden that adversely impacts their health-related quality of life, diminishes their psychological well-being, and increases financial strain on the family [6]. There remains a critical need for structured dialogue and effective cross-sector collaboration among clinicians, therapists, families, researchers, patient groups, and industry. The Duchenne Switzerland Conference 2025 has been pivotal in creating a platform for all stakeholders to share critical insights, identify gaps in care pathways, and bolster collaboration among professionals and caregivers involved in DMD care. Discussions from the conference are vital for enhancing care coordination and developing innovative treatment strategies that can mitigate the disease's impact. This paper presents the main insights from the conference, which was held at the Swiss Paraplegic Centre in Nottwil on 26 September 2025 and brought together over 120 participants from Austria, China, Germany, and Switzerland.

Psychosocial dimensions of DMD care

Several sessions focused on the emotional well-being of patients and families. Talks and discussions highlighted mental health needs throughout the disease trajectory and presented therapeutic approaches to enhancing psychological resilience. A particular focus was the diagnosis phase and the transition to adulthood, which are often marked by stress, uncertainty, and a need for tailored support systems. A recurring theme was the psychological burden associated with repeatedly recounting the child's medical history to various specialists, as well as the ongoing challenge of managing and understanding complex medical information and documentation over time. One keynote focused on resilience as a dynamic and learnable process. Drawing on both developmental psychology and clinical experience, the presenter outlined protective factors that foster psychosocial stability, including trusting relationships, meaningful social connections, positive self-concept, and an informed understanding of the disease. This outcome is further supported by a systematic review revealing that social support – both emotional and tangible assistance – is positively associated with caregiver adjustment, underscoring the protective nature of supportive relationships [7]. The presenter emphasised the importance of supporting emotional processing, self-efficacy, and autonomy through age-appropriate information and open dialogue. These insights align with the contextual model of caregiver well-being proposed by Resch et al. [8], which highlights the interplay between access to resources, environmental supports, threat appraisals, and coping abilities as key determinants of parental well-being.

Digital tools and assistive technologies

Digital innovation emerged as a central theme across multiple sessions. Presenters discussed tools such as electronic health records (EHRs), mobile health applications (e.g. domo.health), and assistive technologies that enable communication, gaming, and environmental control (e.g. Active Communication). One session highlighted the Swiss Electronic Patient Dossier (EPD), a secure, standardised digital health infrastructure, as an EHR example with the potential to improve information exchange across levels of care, reduce redundant procedures, and empower patients and their families. This is echoed by research on the use of EHRs to empower patients through enhanced information exchange [9]. Future developments, such as patient-centred portals and (electronic) emergency cards, were also discussed, along with the challenges posed by data protection and system interoperability. These digital solutions aim to support everyday functioning and long-term care planning. Participants emphasised the need for user-driven design, accessibility, and integration into existing care infrastructures. This suggests that engaging users in a co-creation design and implementation process is essential to ensure that digital health tools meet the needs of patients and caregivers. Furthermore, the presentations demonstrated how digital onboarding for EPDs can be tailored to families with varying levels of digital literacy, thereby expanding access to digital care.

Care research and national networks

Empirical evidence presented at the conference revealed regional inequalities in DMD care within Switzerland. Findings from the Care-NMD-CH project [10] illustrated high satisfaction with care management provided in neuromuscular centres, but also variation in access, quality, and coordination of care. National registries and platforms such as Swiss-Reg-NMD and Myosuisse were recognised as key actors in strengthening data-driven policy and fostering cross-sectoral collaboration. Discussions also addressed how affected families can play an active role in research as experts-by-experience through participatory methodologies and citizen science approaches. These networks can also serve as platforms for co-developing and disseminating best practices.

Participation, empowerment, and inclusion

Parallel sessions explored life with DMD from the perspective of autonomy, inclusion, and lived experience. These sessions, co-designed with affected individuals, addressed empowerment strategies, sports and physical activity (e.g. powerchair hockey), and transition planning. The concept of "self-determination rather than independence" emerged as a recurring theme – a subtle but crucial distinction in long-term care planning. Contributions from the GrowDMD project and lived experience narratives encouraged a shift towards inclusive, person-centred care paradigms that value patient voices and contextual expertise.

Integrating the dynamic model of caregiver wellbeing

The contextual model developed by Resch et al. [8] offers a valuable lens for interpreting insights from the conference. It proposes that parental well-being is best understood as a dynamic interplay between environmental and social supports, individual coping skills, and the subjective appraisal of caregiving demands. Importantly, the severity of the child's condition has less predictive value than access to support systems and the parents' ability to frame their experiences constructively. These findings resonate with the Swiss context of DMD care discussed at the conference; psychosocial strain, fragmented care pathways, and bureaucratic burdens were frequently cited by participants. By explicitly linking digital innovations (such as the EPD) and psychosocial interventions (such as resilience-building and communication training) to this framework, future programmes can better align support services with the real-world needs of families.

Conclusions and outlook

The Duchenne Switzerland Conference 2025 demonstrated the value of inclusive, cross-disciplinary dialogue among families, clinicians, therapists, and researchers in addressing persistent gaps in rare disease care. The strong focus on psychosocial and digital dimensions reflects a growing consensus that comprehensive care must extend beyond medical treatment to incorporate participatory involvement. Digital tools such as the EPD and mHealth apps offer scalable pathways to improve coordination and patient engagement, while psychosocial interventions targeting resilience, coping, and communication are essential for family well-being. Framing these approaches within a contextual and dynamic model of patient and parental well-being helps clarify where structural and emotional support are most impactful. Future efforts should strengthen integration between clinical, technological, and psychosocial systems, while reinforcing participatory structures at every level of care and research. These directions align with broader goals of equity, person-centredness, and sustainability in health systems for rare diseases.

Links

- Active Communication: https://www.paraplegie.ch/activecommunication/de/
- Care-NMD-CH: https://www.zhaw.ch/de/gesundheit/forschung/pflege/projekte/care-nmd-ch
- Domo.health: https://www.domo.health
- Duchenne Switzerland Conference: https://www.duchenne-schweiz.ch/konferenz/
- Swiss Electronic Patient Dossier: https://www.bag.admin.ch/de/elektronisches-patientendossier
- GrowDMD Project: https://www.growdmd.org
- Myosuisse Network: https://myosuisse.org
- Swiss-Reg-NMD: https://www.swiss-reg-nmd.ch/

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Potential competing interests

All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest.

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