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**RISE** Project: Raising awareness for mental health  
in patients and families affected by pediatric neuromuscular diagnosis  
leading to severe disability

# DUCHENNE MUSCULAR DYSTROPHY, USE OF DIGITAL PLATFORMS, AND MENTAL HEALTH CHALLENGES

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## WORKSHOP WITH EXPERTS

We held a virtual workshop with 15 experts, representing patient groups, physicians, parents, and researchers on September 9<sup>th</sup> 2021.

**Goals:** Discuss the most common consequences and mental health challenges in patients and family members, and the most practical and effective approaches for digital interventions to help improve mental health in this group.

## MENTAL HEALTH CHALLENGES and Consequences of the diagnosis for patients and family members

- Living in the nexus between development and degeneration
- Care related challenges
- Social integration related challenges
- Structural and financial challenges
- Access to facilities and care

## Practical and effective approaches and opportunities for digital interventions to improve mental health

New technologies have been developed in the clinical and digital health domains, however, digital approaches that systematically aim at strengthening resilience of patients with muscular diagnoses are still rare. We identified 5 practical and effective approaches to digital health:

- Practical information gathered directly from the affected persons and families
- Information should be tailored to the needs of specific groups
- Information should be targeted to parents and children
- Information should be communicated with respect to cultural age specific and language barriers
- Information on therapists, specialized centers and other helpful resources should be shared

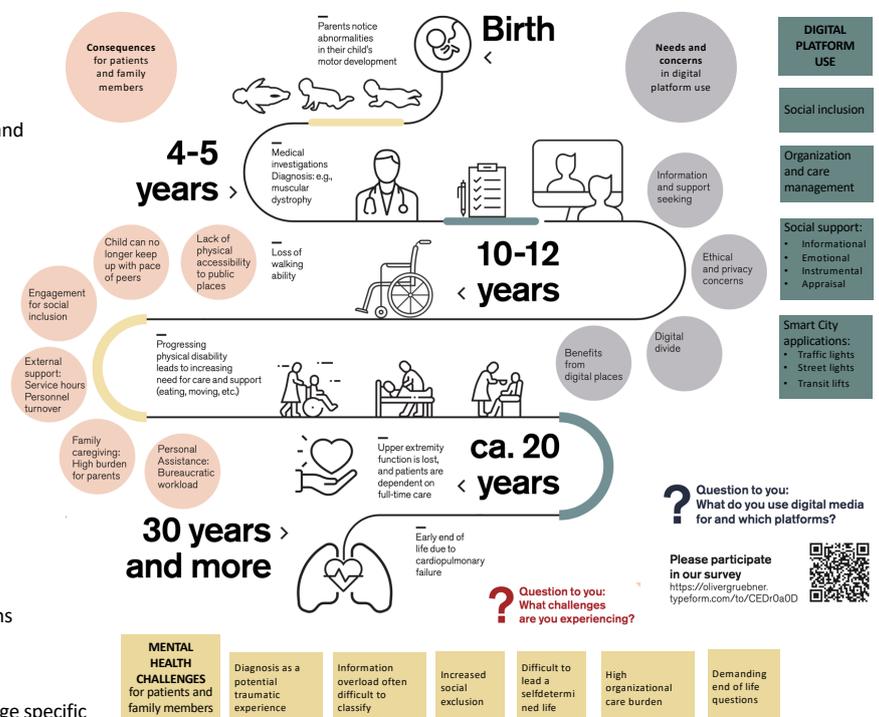
## SCIENTIFIC LITERATURE REVIEW

On **DIGITAL PLATFORM USE** and **MENTAL HEALTH CHALLENGES** for parents and family members of people with pediatric neuromuscular diseases.

**Methods:** Scoping review on English language articles published within the last 10 years for diseases with childhood onset disability and self-help or parent/caregiver-led digital platforms.

**Results:** We identified 17 papers in which digital platforms used by parents of affected children predominantly included social media but also search engines, health-related apps, and medical websites. Main reasons for their utilization where **Information retrieval** and **social support**.

Nearly all studies were exploratory, and applied either quantitative, qualitative, or mixed methods. Main ethical **concerns** for digital platform users included hampered access due to language barriers, privacy issues, and perceived suboptimal advice (e.g., due to missing empathy of medical professionals). Older and non-college educated individuals, as well as ethnic minorities appeared less likely to access information online.



MENTAL HEALTH CHALLENGES for patients and family members	Diagnosis as a potential traumatic experience	Information overload often difficult to classify	Increased social exclusion	Difficult to lead a selfdetermined life	High organizational care burden	Demanding end of life questions
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### What is a Digital place?

A place that offers opportunities for social interaction (=social media) such as you would have in a physical place like a park bench.

### Digital places mentioned in the reviewed literature: Platforms with social interaction

**options:** Facebook, Twitter, Instagram, YouTube, Pinterest, LinkedIn, Skype, Viber, MSN messenger, Yahoo! Answers (operating between June 2005 to May 2021), Yahoo Groups, Quora, Google groups, CaringBridge, CarePages (shut down in 12/2017), and other online forums, blogs, discussion boards, and e-mails.

**Other digital platforms identified:** search engines, medical websites (BabyCenter website, Better Start website, helping children with autism website), and health-related apps.

## CONCLUSIONS

- Limited scientifically sound knowledge exists on digital platform use and needs in the context of disabling conditions in children
- Evidence consists mostly of exploratory studies
- Affected families seek information and support from digital platforms, as the health care systems seem to be insufficient in satisfying the knowledge and support needs through traditional channels.