

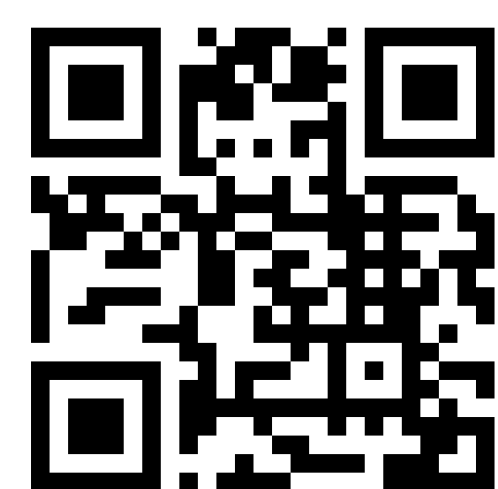
Transition from Pediatric to Adult Care in Duchenne Muscular Dystrophy: Experiences of Patients, Caregivers, and Healthcare Professionals

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Duchenne Muscular Dystrophy (DMD) is a rare neuromuscular condition that significantly reduces life expectancy and quality of life. Despite advances in care the **transition** from **paediatric** to **adult healthcare** remains a challenging phase, often associated with fragmentation and unmet needs for patients and families.

The **“Growing into Adulthood with DMD” (GrowDMD)** project, funded by the European Joint Programme on Rare Diseases 2022, investigates the experiences of adolescents, caregivers, and healthcare professionals (HCPs) across countries during this transition.



OBJECTIVES

- Explore the **experiences** of **adolescents with DMD**, their **caregivers**, and **(HCPs)** during transition to adult care.
- Identify **strategies**, **challenges**, and **recommendations** to optimize transitional care.

METHODS

Qualitative data:

N=74 semi-structured interviews

- 18 **patients** (15–25 yrs)
- 26 **caregivers**
- 30 **HCPs** + Follow-up case vignettes interviews six months later

Quantitative data:

Patients:

- WHODAS 2.0
- PGWBI
- Transition-Q

Caregivers:

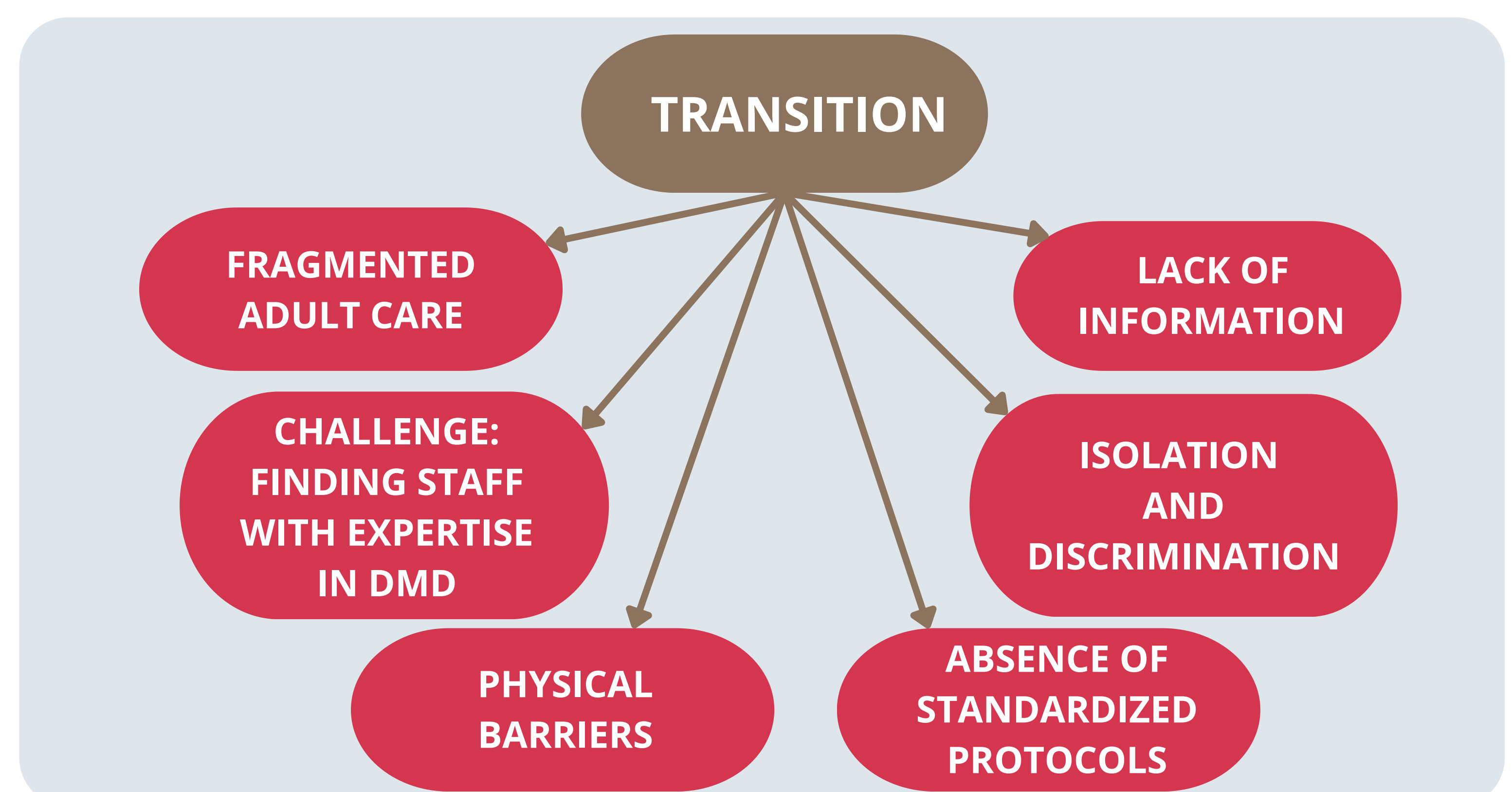
- PEM CY

Data are currently being collected

Countries: Italy, Germany, Canada



RESULTS



CONCLUSIONS

Recent therapeutic advances have **prolonged life expectancy** of people with DMD, making it necessary to update approaches to clinical management. The GrowDMD study identified critical barriers, including **fragmented care systems** and **limited availability of HCPs** in the adult setting. These results highlight the need for **tailored guidelines** to support adolescents with DMD and their families during the transition to adult care.



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